QUEBEC ROUNDTABLE REPORT

Parkinson Canada

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.

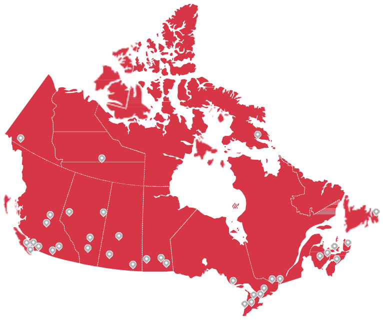
The purpose of the roundtables was to listen to the realities and unmet needs of the Parkinson's community and capture the key issues surrounding Parkinson's healthcare from provincial, territorial, and national perspectives. To support validation of the findings, Parkinson Canada strove for diverse participant representation. People living with Parkinson's, care partners, healthcare professionals, and regional Parkinson's organizations were all 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 the 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 regional report has been created to summarize the unique realities faced by members of the Parkinson's community in Quebec. Following the in-depth discussions from the National Roundtable and building off the eight regional roundtables, Parkinson Canada has identified key priorities for the Parkinson's community to consider to better improve the overall health and quality of life for those living with Parkinson's in Canada.

- Identify and address gaps for additional training and knowledge transfer to qualified healthcare professionals 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 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 dopamine-producing 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, difficulty swallowing, and cognitive impairment, including dementia, can also occur. 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 to 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 wide-reaching 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.[ii]

AN OVERVIEW OF PARKINSON'S IN CANADA

Parkinson's has the fastest growing rates of death and disability compared to other neurological disorders such as MS, dementias, and stroke, and Canada has one of the highest prevalence rates of Parkinson's compared to other countries.[iii]

It is estimated there are more than 100,000 people in Canada living with Parkinson's in 2021.[iv,v] 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 1,400 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 also 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]

AN OVERVIEW OF PARKINSON’S IN QUEBEC

There are over 23,500 people living with Parkinson’s in Quebec. Nearly 25% of people with Parkinson’s in the province report waiting a year or more to receive a formal diagnosis after first reporting their symptoms. The provincial average wait time to meet with a Parkinson’s specialist is seven months.

It is estimated that there is one Parkinson’s specialist for every 2,359 people living with Parkinson’s in Quebec, which is the highest ratio in the country. When surveyed, 55% of people with Parkinson’s in Quebec reported not being a part of a movement disorder clinic.

Nearly 75% of people living with Parkinson’s in the province report having to pay a portion of out-of-pocket expenses for exercise classes and advance care planning support. Furthermore, 42% reported having to pay some portion out of-pocket for physiotherapy, and 26% for medications.

There are over **23,500** people living with Parkinson’s in Quebec.

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Nearly **25%** of people with Parkinson’s in Quebec waited **one year or more** to receive a formal diagnosis.

There is **one** Parkinson’s specialist for every **2,359** people with Parkinson’s in the province.

Close to **55%** of people with Parkinson’s in Quebec reported not being a part of a movement disorder clinic.

Nearly **75%** of people with Parkinson’s in the province pay out of pocket for exercise classes.

ROUNDTABLE DISCUSSION THEMES

Three major themes were focused on during the roundtables. Summarized under each theme are the commonly held perspectives of the participants.

DIAGNOSIS WAIT TIMES

The first topic of the roundtable was diagnosis wait times in the province. Many in the group shared their personal stories on the length of time they had to wait for their general physician to be able to get them an appointment with a neurologist, and even greater wait times were reported for getting in to meet with an MDS. One individual in the group shared her personal anxiety struggles while she had to wait to receive her diagnosis, and the fear of not knowing what was wrong with her.

> "People need a faster diagnosis because medication brings immediate results. When I got sick, I felt like my body was being taken over by the disease. Once I started on the proper medications, it was as if the disease was "pushed out" and I had more control over my movements and overall health."
>
> - Person living with Parkinson's, Quebec City, Quebec

A member in the group who has young-onset Parkinson's shared her belief that a lot of general practitioners have a challenging time with identifying the early signs of Parkinson's and suggested that better knowledge and education on the disease would lead to faster and better diagnosis.

The group then heard from a participant who reflected on his journey with being diagnosed and shared how he was bounced between several doctors before finally being told he had Parkinson's. One of the doctors that he consulted with told him that he wanted him to take the Parkinson's medication, Levodopa, and that if it helped with any of his symptoms then he would know that he had Parkinson's. He went on to share that he had to spend a lot of time on Google researching Parkinson's because he was not getting enough information about the disease, or its symptoms, from any of his medical appointments.

ACCESS TO CARE

The next topic of discussion was access to care. Members of the group agreed that when it comes to managing Parkinson's, a multidisciplinary approach to healthcare is essential. Allied healthcare services such as physiotherapy, occupational therapy, speech therapy, massage therapy, and optometry were just some of the examples of services that members of the group listed as being beneficial.

One member of the group shared his belief that he would benefit from having a care coordinator, as well as someone who would be able to council him through understanding his Parkinson's symptoms, teach him about the interactions of various Parkinson's medications and their effects, and be someone he could talk to and seek support from emotionally.

> "Quebec needs more movement disorder clinics offering a multidisciplinary care team."
>
> - Person with young-onset Parkinson's, Montreal, Quebec

A care partner who was in attendance agreed with this thinking and shared how she believes that the idea of care coordination through a centralized medical clinic for Parkinson's would have been beneficial for managing her father's Parkinson's. Most of the group agreed with this point, sharing their own personal stories of how it would have been beneficial upon receiving a diagnosis of Parkison's to have been connected to care coordinator to assist them with both information on the disease and scheduling appointments with a care team.

> "We need a leader for care. A neurologist will say 'here's the care plan,' but then someone else will come along and say 'actually, this is the plan' – we need everyone in the care team to have consensus from the beginning. A manager or team lead for Parkinson's care would be a real benefit."
>
> - Care partner, Montreal, Quebec

Several members of the group then discussed the importance of exercise for managing both their physical Parkinson's symptoms and their mental health. It was shared by multiple members that Parkinson Quebec offered exercise classes online that people could access at any hour of the day.

MODEL OF CARE

The final topic of the roundtable was on a model of care for Parkinson's. The conversation continued about care coordination from the previous topic. One member of the group shared how there are many resources that are required to be coordinated for managing Parkinson's. With the disease being degenerative, she went on to share how it is a constant evolution of treatment needs and trying to stay on top of it all, especially if you are alone, can be quite overwhelming.

> "The key is to find a group of people for support. By having a group of people, you can learn much more quickly than if you were doing it alone."
>
> - Person living with Parkinson's, Quebec City, Quebec

A care partner in the group mentioned how Parkinson Quebec has been great with helping her husband with providing contacts to allied healthcare services and other resources. Another care partner, whose mother has Parkinson's, shared how beneficial it would have been to both her mother's care and for her own support as a care partner, to have had a network or support group in place that could have been there to provide resources or useful information about the disease.

The idea of a mobile app was then raised by a member of the group. It was suggested that it could store useful information about the person with Parkinson's and be accessible by all members of the individual's care team. This would help ensure that all the most up to date notes on progress are being logged and could help to keep each member of the care team informed. She then went on to add that it would be useful if it had a mental health component that could give a patient direct access to a helpline or support group chat.

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 its 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 the 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 affected by 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 health care outcomes for people living with Parkinson's across Canada.

https://www.parkinson.ca/

APPENDIX

[i] Deep Brain Stimulation. (n.d.). Sunnybrook Health Sciences Centre. Retrieved January 7, 2022 from https://sunnybrook.ca/content/?page=deep-brain-stimulation

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[iv] Public Health Agency of Canada. Canadian Chronic Disease Surveillance System (CCDSS), Data Tool 2000–2016, 2018 Edition. Ottawa (ON): Public Health Agency of Canada; 2019.

[v] Neurological Health Charities Canada (NHCC), Health Canada, Public Health Agency of Canada (PHAC), Canadian Institute of Health Research (CIHR). MAPPING CONNECTIONS: An Understanding of Neurological Conditions in Canada. Sept. 2014. pg.68.

[vi] People with Parkinson's Face Gaps in the Availability of Health Services [Data Set] (March 28, 2018). IPSOS Public Affairs. Retrieved December 17, 2021 from https://www.ipsos.com/en-ca/news-polls/parkinson-canada-stakeholder-survey-2018

[vii] Parkinson Canada National Environmental Scan conducted in Fall 2018

[viii] Mathematical estimate based on [v, vii]

[ix] R-1 March Interactive Data. (May 13, 2020). CaRMS. Retrieved December 15, 2021 from https://www.carms.ca/data-reports/r1-data-reports/r-1-match-interactive-data/

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To obtain additional information, please contact:

Parkinson Canada
211 Yonge St. Suite 316 Toronto, Ontario M2P 2A9
Tel: 416.227.9700
Toll Free: 1.800.565.3000
Email: advocacy@parkinson.ca
Media contact: media@parkinson.ca