ATLANTIC REGION 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.

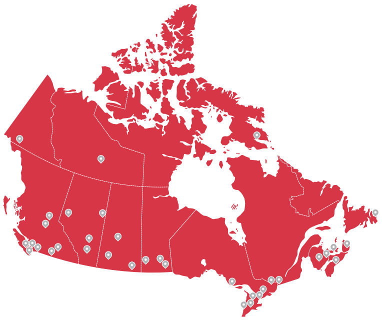
The purpose of the roundtables was to listen to the realities and unmet needs of the Parkinson's community and capture the key issues surrounding Parkinson's healthcare from provincial, territorial, and national perspectives. To support validation of the findings, Parkinson Canada strove for diverse 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 the Atlantic region. 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, 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 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 is one of the fastest-growing neurological diseases in the world and Canada has one of the highest prevalence rates 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 THE ATLANTIC REGION

There are over 6,000 people living with Parkinson’s in the Atlantic provinces. For this region, the average wait time to see a Parkinson’s specialist is two years or greater, which is significantly higher than the national average wait time of 11 months. Prince Edward Island does not currently have a Parkinson’s specialist on the island.

Nearly 30% of people living with Parkinson’s in the Atlantic report waiting a year or more to receive a formal diagnosis after first reporting their symptoms to a medical professional.

When surveyed, close to 40% of people with Parkinson’s in the Atlantic reported not being a part of a movement disorder clinic.

People with Parkinson’s in the Atlantic region report having to pay a portion of healthcare expenses out of pocket. Roughly 70% of those surveyed report paying out of pocket for exercise classes and palliative care, and 30% say they have paid out of pocket for medications, as well as physiotherapy.

There are over **6,000** people live with Parkinson’s in the Atlantic region.

1+

Nearly **30%** of people with Parkinson’s in the Atlantic region waited **one year or more** to receive a formal diagnosis.

There is **one** Parkinson’s specialist for every **1,298** people with Parkinson’s in the region.

Close to **40%** of people with Parkinson’s in the Atlantic reported not being a part of a movement disorder clinic.

70% of people with Parkinson’s in the region pay out of pocket for exercise classes and palliative care.

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 region. The consensus amongst the group was that for earlier diagnosis to be possible, further education of Parkinson's is required for general practitioners. 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.

> "I had three neurologist appointments before being diagnosed and getting the right medication was a two-year process."
>
> - Person living with Parkinson's, Fredericton, N.B.

A movement disorders specialist who attended the roundtable echoed the sentiments shared by the group and discussed how there are many general practitioners who are uncomfortable making a diagnosis due to a lack of education about the disease, and how it is challenging for them because there are no tests for accurately diagnosing Parkinson's.

ACCESS TO CARE

The next topic of discussion was access to care. One member in the group who has Parkinson's shared his belief that a multifaceted approach to healthcare is essential when managing his symptoms. 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. Several members of the group also discussed the importance of exercise for managing both their physical Parkinson's symptoms and their mental health.

One major barrier for people living in remote parts of the region who have Parkinson's are the out-of-pocket travel expenses to major cities for medical appointments with either a neurologist, or MDS. The entire Atlantic region has only five MDSs that are available to meet with Parkinson's patients and they are spread out across Nova Scotia, Newfoundland & Labrador, and New Brunswick. There is currently no MDS on Prince Edward Island.

One member of the group who works for a Parkinson's community organization based in Newfoundland shared that there is a shortage of neurologists and general practitioners in the province, as well as other allied healthcare services, such as physiotherapy, occupational therapy, speech therapy, etc.

MODEL OF CARE

The final topic of the roundtable was on a model of care for Parkinson's. The conversation shifted towards virtual healthcare. Several members of the group agreed that since the beginning of the COVID-19 pandemic, virtual medical appointments have been incredibly convenient and have spared people a lot of time and financial costs with not having to travel. Particularly for those living in more remote parts of the Atlantic region.

> "It can be more time efficient being on video, but you cannot make a diagnosis over ZOOM. The challenge is also with timely follow-ups. You need ongoing follow-ups for years and years."
>
> - Movement disorders specialist, Halifax, N.S.

On the other end of the spectrum, a movement disorders specialist who attended the roundtable felt that virtual care and telemedicine can be challenging for her to accurately assess patients. As an MDS, she stressed how important it is to be able to see a patient in person so that she can see how their mobility and range of motion are doing. While convenient in some respects, there are limitations to what benefits a medical practitioner can provide to their patients with a virtual healthcare model.

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

[ii] Duodopa® Therapy. (n.d.). University Health Network Krembil Brain Institute. Retrieved January 7, 2022 from https://www.uhn.ca/Krembil/Treatments_Procedures/Duodopa_therapy

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

[viii] Mathematical estimate based on v, vii

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