TERRITORIES ROUNDTABLE REPORT

| Parkinson Canada

Parkinson Canada

CONTENTS

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.

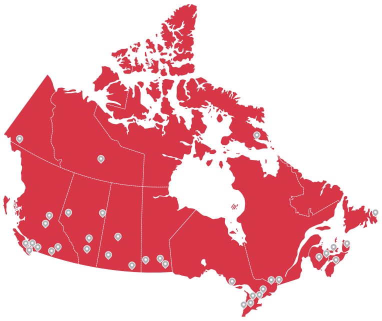
The purpose of the roundtables was to listen to the realities and unmet needs of the Parkinson's community and capture the key issues surrounding Parkinson's healthcare from provincial, territorial, and national perspectives. To support validation of the findings, Parkinson Canada strove for diverse 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 territories. 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 disease of the brain caused by the loss of certain brain cells producing a chemical called dopamine. These dying brain cells are in areas of the brain involved in coordinating movement. Individuals with Parkinson's may experience a resting tremor, slowness of movement, muscle rigidity, and balance problems. While Parkinson's is commonly thought of as a movement disorder, non-motor symptoms such as anxiety & depression, sleep issues, 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 50 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. 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 disease has the fastest growing rates of death and disability compared to other neurological disorders such as dementias, MS, and stroke and Canada has one of the highest prevalence rates of Parkinson's compared to other countries.[iii]

It is estimated there were 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]

There are approximately **60** people living with Parkinson's in the Northwest Territories and Nunavut

3

On average, general neurologists will travel to the territories once every **three months**

There are **0** Parkinson's specialists in the Northwest Territories, Yukon, or Nunavut

1+

People living with Parkinson's in the Northwest Territories can wait **over a year** to meet with a general neurologist

AN OVERVIEW OF PARKINSON'S IN THE TERRITORIES

Currently, there are no Parkinson's specialists in the Northwest Territories, Yukon, or Nunavut. As a result, small teams of general neurologists travel in from outside of each territory.

In the Northwest Territories, it is estimated that there are 30 people living with Parkinson's. [iv] Neurologists will travel in from Calgary to the Ambulatory Care Centre at Stanton Territorial Hospital in Yellowknife every two to three months and, for each visit, stay one week on average. Some of these neurologists specialize in stroke, brain injury, and MS. Wait times to meet with these neurologists can vary, with some being seen within a month and others who report wait times of one year or greater. People living with Parkinson's in the territory must travel to Edmonton to receive Deep Brain Stimulation (DBS) treatments.

Nunavut also have approximately 30 people living with Parkinson's. [iv] A team of two neurologists travel from outside of the territory to the Qikiqtani General Hospital three times per year. For each visit, the neurologists will stay one week on average.

The Yukon has three visiting neurologists who travel to the Whitehorse General Hospital every three months from outside of the territory. Two of the neurologists are generalized, and one specializes in MS.

All three of the territories' visiting neurologists mostly stay within the capital cities, posing a geographical barrier to their services for those living in rural communities.

While access to Parkinson's medication is available in all three territories, there are some drugs that are either unavailable, listed under "exceptional" drug status, or require prior approval, posing access barriers for individuals living with Parkinson's.

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

There are no Parkinson's specialists, also known as Movement Disorder Specialists, or general neurologists that are based in the territories. A member of the group who lives in Yellowknife, Northwest Territories has been showing signs of Parkinson's symptoms for a couple of years and has been waiting over a year to receive a proper diagnosis. She has been seeing a doctor off and on for the past two years with health concerns but has been frustrated by the ongoing wait and other "unknowns" for her health, with no answers. She went on to share that she is on medication, but they mostly just put her to sleep. She has tried to access doctors in Comox, British Columbia; however, they were not accepting new patients. More than anything, she would just like to be able to talk with a Parkinson's specialist on the phone, or even with another person living with Parkinson's to learn more about the condition. Ultimately, having a diagnosis would be life changing as it would allow access to allied health services.

> "If you aren't formally diagnosed, you don't get access to tools and resources such as neurologists."
>
> - Person with Parkinson's, Yellowknife, Northwest Territories

Another member of the group in Yellowknife who is a care partner for her father with Parkinson's, shared her frustration with the lack of doctors in the region. She went on to add that in their experience, some family doctors have had to Google Parkinson's to know what to do for her father's care. Wait times between appointments can be upwards of three months apart. Neurologists who travel in periodically to Yellowknife have such long wait lists that most often they will only see emergency cases. If you are fortunate to get an appointment, it is typically very brief and there is no continuity of care or relationship that is formed with the doctors.

> "Wait times are about six months to one year to see a neurologist. You must travel into the city and the appointment is only 15 minutes."
>
> - Care partner, Whitehorse, Yukon

A care partner who is a physiotherapist in Whitehorse had suspected her husband had Parkinson's and had to ask a doctor friend to write a note to get them an appointment with a neurologist. They then had to travel to Edmonton for the appointment and during the consultation, the neurologist suspected that her husband had been living with Parkinson's for close to a decade. She went on to share her belief that their family doctor was unable to connect the dots, which resulted in a delay in her husband's diagnosis.

ACCESS TO CARE

Since the COVID-19 pandemic began, virtual care has been a life changing experience for several members of the group. One individual shared that thanks to an increase in virtual care, she managed to get her father connected with a Movement Disorder Clinic for the first time ever. In addition, their pharmacist has been extremely helpful and knowledgeable about Parkinson's. The pharmacist has given full consultations with the family about medications and has even reached out to doctors on their behalf.

A physiotherapist for the Nunavut Department of Health who lives in Iqaluit shared with the group that neurologists come to Nunavut twice a year for one week at a time. In the winter, it can be particularly challenging for people based in rural communities to travel to the city for appointments. Furthermore, follow-up appointments can take one to two years. In some of the remote areas of the territory, people rely on nurses for care and referrals, but it can take a long time to get the appointments with doctors. Community doctors will fly into rural parts of Nunavut and may be able to see patients every six to eight weeks, often to give medication adjustments.

A member in the group from Whitehorse agreed that virtual care has been a benefit to her family as well. In comparison to face-to-face appointments with neurologists who are out of town, their virtual appointments will spend one hour or more with her husband on a call. She went on to share that their pharmacist is also a valuable resource but does not do the same level of advocating on their behalf as with the care partners pharmacist in Yellowknife. Her belief is that doctors in the territories try to discourage patients from accessing further specialized care.

> "I'm not sure how someone would manage Parkinson's in the territories by themselves. You get an appointment with little direction and then are sent home. It required a lot of advocating on my part. If not for support from people like me, you are just sent home to suffer."
>
> - Care partner, Yellowknife, Northwest Territories

It was also raised by members of the group how virtual care has allowed them to attend appointments with greater ease. One member shared how her parents do not have their driver's license, so for them to get to a physical appointment would be impossible without her needing to take time off work to drive them. Virtual care takes the hassle of travel away and it allows for people to access actual Parkinson's specialists directly from home.

Virtual care could be solution for healthcare nationwide because you would no longer need to always go into an office to meet with a general practitioner who barely knows anything about Parkinson's and just prescribes medications. It would connect people to actual Parkinson's specialists who could provide a faster and easier diagnosis process.

A physiotherapist with the Government of Health for Nunavut weighed in and shared with the group that many of her patients are Inuit and they do not like virtual care. Many view the concept of virtual care as being "lazy," as though the healthcare team does not want to make the effort to see them in person.

> “I would like to just be able to talk to a Parkinson’s specialist on the phone, or even just talk to someone with Parkinson’s to connect and learn from.”
>
> - Person with Parkinson’s, Yellowknife, Northwest Territories

The topic of support groups was then raised. There was a sense of discouragement shared from several members of the group about the lack of support group presence in the region. A person living with Parkinson’s in Yellowknife strongly agreed with this point and thinks that support groups would be helpful, by having someone that she could talk to and learn more about her Parkinson’s. The care partner in Whitehorse was unaware of any support groups in the Yukon but has been fortunate to find some connections through an online speech therapy group who live in her region. In Nunavut, most of the population are Inuit and many of them do not have internet or phones, so support groups are not a benefit for them or much of an option.

The group was then asked about other types of healthcare services that they access. Both physiotherapy and occupational therapy through virtual care were mentioned. Additionally, a nurse and a dietician have been beneficial to several members of the group.

> “I went to a psychologist, and he gave me breathing exercises. I asked for a speech therapist, and they said I did not need one. When you get stressed, you can’t speak, or you mumble and get asked to repeat yourself and it is frustrating. In my opinion, they go together.”
>
> - Person with Parkinson’s, Yellowknife, Northwest Territories

The care partner in Yellowknife then shared her belief in the importance of speech therapy. Her father can be very self-conscious because in the past people have presumed that he was drunk when trying to communicate. She finds that their experience with psychologists has not always been positive, as they will talk down to her father or speak to her rather than to him directly. She then went on to share again how much support their pharmacist has provided. The family also consulted with a dietician who had no knowledge of Parkinson’s and was only focused on increasing her father’s weight. The dietician was giving him protein powder, which was impacting the effectiveness of his medications. Some of the recommendations were hurting him and not helping him.

It is important that health care practitioners have the necessary knowledge and expertise to work with Parkinson’s patients, or at the very least acknowledge if they do not have the proper education as to not risk causing more harm than beneficial care.

MODEL OF CARE

The conversation of a model of care led to the topic of medical travel support. A care partner in Whitehorse shared that they have medical travel. Their travel is paid, and they get a daily allowance for food and accommodation. As the care partner, she receives payment as well and the government pays for all their medical appointments. With that said, the amount they receive of $120 is not enough to cover the cost of both food and accommodation entirely, so there are still some expenses that must be paid out-of-pocket. Certain airlines will allow care partners to travel for free or at a reduced cost. Medical travel will book your flights for you, but you are responsible to book everything else (e.g., hotel, taxi, food, etc.).

The care partner from Yellowknife shared that they also receive government support for medical travel, and they also have Alberta Blue Cross coverage for seniors that helps with even more expenses (medications, home care support, etc.).

In Nunavut, medical travel benefits are quite good in the region. Inuit residents have accommodations in Ottawa provided to them.

The topic then shifted to homecare services offered in the territories. In Whitehorse, a care partner shared that homecare support is available to them. They used to have someone come to their home every day until the start of the COVID-19 pandemic. Now, they can't have support workers over, because no one will tell them which support workers are vaccinated and there is currently no government requirement. Nunavut also has homecare services, but their major barrier is staffing. Iqaluit has a much better program for homecare services that provides nurses and a physician.

> "A lot of provinces allow you to pay for private homecare, but around here there is only government homecare and there is a limited number of hours per week that are available. They only offer support during the day, but it would also be beneficial to offer support outside of standard business hours."
>
> - Care partner, Yellowknife, Northwest Territories

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

[iii] Dorsey, E. R., Elbaz, A., Nichols, E., Abd-Allah, F., Abdelalim, A., Adsuar, J. C., … Collado-Mateo, D. (2018). Global, regional, and national burden of Parkinson's disease, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. The Lancet Neurology. doi:10.1016/s1474-4422(18)30295-3

[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]

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