

ONTARIO 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.

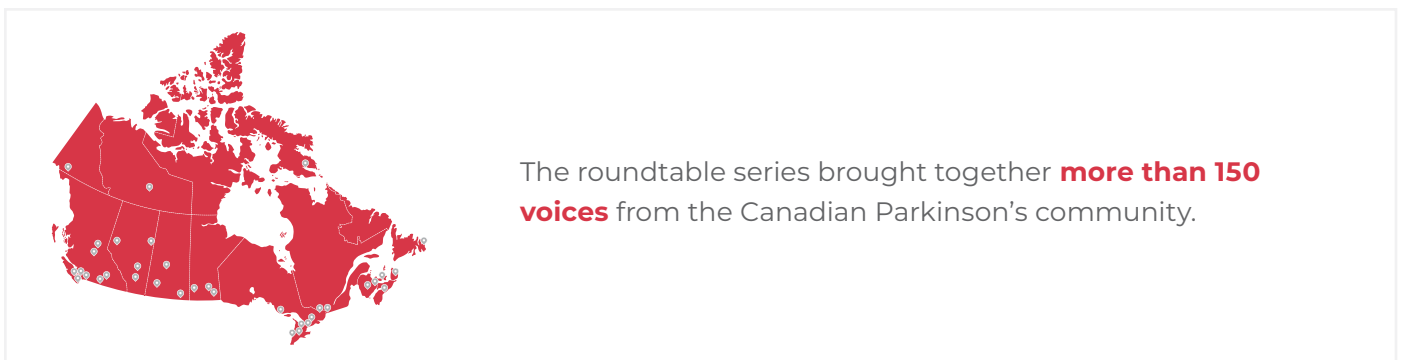
The purpose of the roundtables was to listen to the realities and unmet needs of the Parkinson's community and capture the key issues surrounding Parkinson's healthcare from provincial, territorial, and national perspectives. To support validation of the findings, Parkinson Canada strove for diverse 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 Ontario. 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.



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}

AN OVERVIEW OF PARKINSON'S IN ONTARIO

With over 46,000 diagnosed, the province of Ontario has the most individuals living with Parkinson's in Canada.^{ix} The provincial average wait time to meet with a Parkinson's specialist was 11 months in 2018.^{vii}

It is estimated that there is only one Parkinson's specialist for every 1,379 people living with Parkinson's in Ontario.^{viii}

Most of the Parkinson's specialists in Ontario are in major cities across the southern portion of the province. Similarly, many Parkinson-specific services are centralized to urban regions of the province posing geographical access barriers to residents in northern or rural areas.

Over 50 per cent of care partners in Ontario feel they do not have sufficient access to information or resources to properly care for the person with Parkinson's in their lives.^{vi}

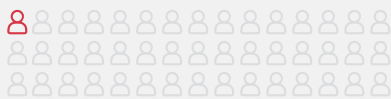
Many Ontarians living with Parkinson's are required to pay out of pocket for critical healthcare services. It is estimated over 50 per cent of individuals pay out of pocket for exercise programs and physiotherapy. Furthermore, 25 per cent of individuals report paying a portion of their medication costs out of pocket.^v



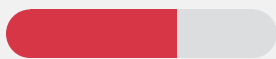
There are more than **46,000** people living with Parkinson's in Ontario.



The provincial average wait time to meet with a Parkinson's specialist is **11 months**.



There is **one** Parkinson's specialist for every **1,379** people with Parkinson's in the province.



54% of care partners in Ontario feel they do not have sufficient access to information or resources.



Over 50% of individuals pay out of pocket for exercise programs and physiotherapy.

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

Diagnosis wait times are a challenge in the province. A member in the group who is a movement disorders specialist shared that in her experience, general neurologists are excellent at diagnosing Parkinson's; however, there is a bottle neck that occurs for people who are waiting to get in for an appointment, with some wait times being two to three years.

Several members in the group who are living with Parkinson's agreed with this opinion, with one individual sharing that he had to wait at least a year before being able to be diagnosed after being passed from his general practitioner to a neurologist, and then finally to a movement disorder specialist before finally being diagnosed with Parkinson's.

Another movement disorders specialist who recently completed her fellowship then shared that there is an average wait list of one to two years to get into her clinic and that most of those who come to see her have already been to a neurologist beforehand.

“It is important to get an early diagnosis, so that you can be connected to the right resources and get on the medications you need to prevent any suffering to the quality of one's life.”

- Movement Disorder Specialist, Toronto, ON

Further education of Parkinson's for general practitioners was widely discussed amongst the group. A movement disorder specialist in the group agreed that targeting general practitioners with more Parkinson's education would be beneficial, but also acknowledges that it could be a challenge with the limited number of Parkinson's patients that the average general practitioner has in their clinic. Other members of the group weighed in on this and agreed that more education is needed for family doctors.

One woman with Parkinson's explained that after her experience of receiving a diagnosis, there was not really any additional information or resources provided. Without being given proper information, she turned to Google for answers and acknowledged that the internet can certainly be useful; however, there is also a lot of misinformation online. There is a greater need for the right information at the right time.

When you get the diagnosis, what resources should you get? Who should you go to? Whoever gives you the diagnosis, needs to be better educated on what to give you when you are leaving the room.

“At the time of my diagnosis, it seemed like it was a surprise - that no one had a plan for what was next. There was no process for you have Parkinson’s...now what?”

- Person with Parkinson’s, Toronto, ON

On the end of the spectrum, there were members in the group who shared that they were fortunate to receive a quick diagnosis for either themselves or their partners. One woman in the group living with Parkinson’s shared with the group that she was quickly diagnosed, but she is a part of several support groups and has heard many stories over the years of people struggling to get a diagnosis.

The group was then asked about what barriers are experienced for receiving diagnosis. A member in the group raised societal behaviours and stigma as a barrier that he experienced when receiving his Parkinson’s diagnosis. When he was first experiencing symptoms, he was working with a lot of medical colleagues who were telling him that he could not have Parkinson’s because he was “too young.” These kinds of experiences from his peers placed doubts in his mind that prevented him from pursuing further investigation into his symptoms sooner with his family doctor.

Overall, there was a consensus amongst the group that another barrier of receiving a diagnosis is the actual quality of the diagnosis experience with their physician and not just necessarily the timing of the diagnosis.

“The diagnosis is an important stage to go beyond. Once you are diagnosed properly, you can start to accept it and make changes that will help you start to manage this disease and build your healthcare team. The sooner you can get diagnosed, the sooner you can start down this path.”

- Doctor living with Parkinson’s, Toronto, ON

ACCESS TO CARE

The next topic of discussion was access to care. Members in the group discussed the importance of a holistic healthcare team approach to managing Parkinson's symptoms. Many in the group agreed that Parkinson's and its symptoms are unique to each individual and it is important to have a variety of allied healthcare services to address many of the different symptoms that are faced with the disease.

“Collaboration is key. There is a lot of education that needs to happen in our healthcare system in both the hospitals and the community.”

- Parkinson's Nurse, Ottawa, ON

It was then raised by a member in the group on the importance of allied healthcare professionals to be properly educated on Parkinson's to help provide a better quality of care for their patients that will effectively target symptoms.

“With Parkinson's disease, it is about person-centered care because it affects people differently. I think people do better when they are managed by a team of healthcare professionals. The team is going to change from person to person, and how they help will change, because it is such a variable disease.”

- Person with Parkinson's, Toronto, ON

Many in the group believed that collaboration amongst healthcare professionals is key to provide an effective care model for Parkinson's. The topic of care coordination for those who are newly diagnosed with Parkinson's was then raised by several members of the group who believe a nurse care coordinator could help provide the right information and resources after being diagnosed and could also assist with scheduling appointments for various allied healthcare services (physiotherapy, occupational therapy, dietician, fitness training, optometry, etc.). Currently, there is not a model of care coordination that exists for Parkinson's in the province that integrates resources for Parkinson's patients and many in the group felt would be beneficial.

Geographic location within the province was raised as a barrier to accessing treatments. For those who live in rural parts of the province, they must drive great distances and spend money for travel and accommodation to attend appointments to receive treatments that are not offered in their local communities. With limited finances, this can be challenging, or even unattainable. The idea of having a nurse care coordinator model would be ideal if it were to also exist within rural communities, as well as in major urban centres across the province.

“There are no health care professionals in Cornwall. People there must travel to Ottawa, Kingston, Brockville, and sometimes even Montreal. Can people afford to travel? Will people need someone to take them?”

- Person with Parkinson's, Cornwall, ON

A member in the group with Parkinson's stated that is valuable to have a financial advisor as part of your care team, as they can be important with assisting in building a plan to afford long-term care. If you are unable to work due to Parkinson's, which results in limited income and no health benefits, the expenses associated with many of the allied healthcare services come out-of-pocket and that can play a key role on the mental health impact to either the person who is living with Parkinson's, or on their care partner.

MODEL OF CARE

The final topic of the roundtable was on a model of care for Parkinson's. The group was asked if anyone has experienced integrated care. A care partner in the group shared that her husband experienced a care model when he went to Baycrest in Toronto (Baycrest is an academic health sciences centre that provides care for older adults, including independent living, assisted living, long-term care, and a post-acute hospital all within one campus).

“Everything was on one day in one place. After we left the centre, we would hear from a social worker who made all the arrangements for anything we needed outside of the clinic.”

- Care partner, Ottawa, ON

The care partner went on to share with the group that while attending Baycrest, her husband first met with a nurse at the facility who took down notes and then they were sent to meet with a movement disorder specialist who reviewed through the nurse's notes to determine what allied healthcare services should be explored further for treatment options (physiotherapist, dietician, etc.). All the allied healthcare professionals were based at the Baycrest facility, so everything was done onsite and each of them would work off the same set of notes that were initially provided by the nurse. After leaving the facility, a social worker would periodically reach out to them and would help arrange for any services that were outside of the facility.

A movement disorder specialist in the group agreed that it is important to manage your care when you have Parkinson's and always refers his patients to various allied health services, such as physiotherapy, occupational therapy, speech pathology, etc.

Another movement disorder specialist fully supported this statement and believes that a Parkinson's-focused centre is an important concept, especially with the prevalence of the disease in Canada.

There was an overall agreement from most in the group that a team approach to caring for Parkinson's healthcare would be an ideal scenario. However, there was also concern from some about whether this is a realistic outcome with the limited number of neurologists and movement disorder specialists across the province in comparison to population of people in Ontario who are living with Parkinson's. It was suggested that a collaborative team approach with other doctors (e.g., general practitioners) and other resources could help. It was then raised by a member in the group if whether Parkinson Canada could become a "one stop shop" for information and resources within local communities and help connect people to healthcare and support services. There were also some questions raised about what the cost to run multidisciplinary facilities like these would look like year-over-year.

"Self-management is an integral part of your Parkinson's. It varies so much hour to hour, so you are not always getting an accurate response. You need to be the quarterback of your healthcare team."

- Doctor living with Parkinson's, Toronto, ON

A person in the group living with Parkinson's stated how critical it is for patient education. After receiving diagnosis, it is not only important for you to be given the proper information and resources about the disease, but also to ensure that you do your own research and should get yourself connected to a support group (either in-person, or online).

There was also discussion about utilizing technology to help support this kind of care model. A member in the group mentioned the need for electronic health records that could easily be shared between healthcare providers in a shared online database.

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}

^{ix} Mathematical estimate based on ^{iv}

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