MANITOBA 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.

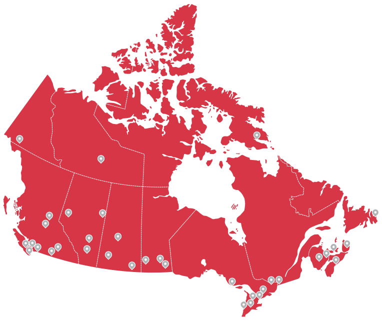
The purpose of the roundtables was to listen to the realities and unmet needs of the Parkinson's community and capture the key issues surrounding Parkinson's healthcare from provincial, territorial, and national perspectives. To support validation of the findings, Parkinson Canada strove for diverse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

AN OVERVIEW OF PARKINSON'S IN MANITOBA

It is estimated that there are over 4,000 people in Manitoba living with Parkinson's today.[ix] Each year, approximately 450 people in Manitoba are newly diagnosed.[iv] To support this population, there are only four Parkinson's specialists throughout the entire province.[vii] That is one Parkinson's specialist per 1,018 people living with Parkinson's in Manitoba.[viii]

The average provincial wait time to see a Parkinson's specialist was eight months in 2018.[vii] Notably, all four specialists are in the province's capital, Winnipeg, posing a geographical challenge for individuals living in more rural areas. Additionally, most allied healthcare professionals are likely to reside within the provincial capital resulting in a barrier to their services for those in rural communities.

Manitoba does not currently have a Deep Brain Stimulation (DBS) surgeon residing within the province and relies on the travelling services of a surgeon from Calgary. As a result of this, wait times of two years or more are common.

In comparison to other provinces, access to Parkinson's medication in Manitoba is challenging. Certain medications (e.g., Stalevo) are not funded by the provincial formulary, while others are listed under "exceptional" drug status posing further access barriers for individuals living with Parkinson's.

Estimated **4,000** people living with Parkinson's in Manitoba

8

The average provincial wait time was **eight months** to see a Parkinson's specialist in 2018

There is one Parkinson's specialist for every **1,018** people with Parkinson's

2+

Average wait time for an appointment to see a DBS surgeon in 2018 was **more than two years**.

ROUNDTABLE DISCUSSION THEMES

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

DIAGNOSIS WAIT TIMES

When participants of the Manitoba Roundtable were polled, 57 per cent felt that diagnosis wait times are a challenge in their region. At the beginning of the roundtable discussion, it was presented to the group that the current average wait time for receiving a diagnosis in Manitoba was eight months. However, two Parkinson's specialists in attendance shared with the group that wait times are much less and that the average wait time for the province is around four and a half months.

> "Two months from onset symptoms to diagnosis would be ideal, but that will be hard to get in Canada without more specialists and more knowledge for family doctors."
>
> - Parkinson's Specialist, Winnipeg, Manitoba

A person living with young-onset Parkinson's in the group shared his story of receiving a diagnosis and how it was a much lengthier process of two years. When first approaching doctors about their concerns, it was initially believed to be a mental health "problem". After having several tests done, including an MRI, their first neurologist consultation told them that they were too young to worry about it being Parkinson's and dismissed the idea. Throughout their process of receiving diagnosis, it became discouraging when being turned away and then having to wait several more months until being able to get another appointment.

One of the Parkinson's specialists in attendance supported this anecdote and shared that while it is a much faster process for those who are older to receive a diagnosis; the story of delayed diagnosis for younger patients is common. It was also shared with the group that the COVID-19 pandemic has caused a delay in referrals to their clinic, which has also caused delays in being able to properly diagnose patients.

> "A lot of physicians and nurses have no idea what Parkinson's is and how to work with it. There needs to be more time spent educating people about it, especially nurses."
>
> - Clinical Resource Nurse, Winnipeg, Manitoba

A clinical resource nurse at a movement disorder clinic shared that a lot of people and clinicians aren't aware that their clinic exists, so often there are many who don't get referred to them by their doctors. One of the movement disorder specialists agreed with this point and stated the importance of public awareness for Parkinson's. It would be possible to have more people diagnosed earlier if they, and their doctors, could recognize and identify symptoms sooner.

A geriatrician in attendance offered their insights with working with elderly patients who are very advanced with Parkinson's and have never been diagnosed. They then went on to share how crucial it is to get these people on the right medications that will help with their overall quality of life.

Stigma plays a role in delays for diagnosis, especially for those who present symptoms at a younger age. If there is a general lack of knowledge about Parkinson's amongst colleagues or peers, there can be major concerns about sharing their diagnosis and how it could affect their career, or other aspects of their life.

> "I couldn't tell anyone about it at work because they wouldn't know what I'm capable of doing, or not doing. I didn't want them to judge my abilities."
>
> - Person living with early onset Parkinson's, Winnipeg, Manitoba

ACCESS TO CARE

When asked about healthcare services and their availability in the province, one of the group members living with Parkinson's shared that everyone's experience with Parkinson's is unique to them and that there needs to be a variety of treatment options on offer. A multidisciplinary approach would be key to treating Parkinson's.

The topic of geographic barriers then came up as one of the Parkinson's specialists shared their belief that people in rural parts of Manitoba are at a huge disadvantage and doing full Parkinson's assessments through telehealth (such as ZOOM) is difficult. The geriatrician in the group echoed these thoughts and shared disbelief with how far some will travel to receive treatments in the province's urban centres. For those who live in rural communities, they will often travel three hours or more to go to an appointment.

The geriatrician then went on to share that there are currently no real care managers for Parkinson's patients. Family doctors will tend to act in that role, but not always have the time to commit to it. In their opinion, Geriatricians and geriatric mental health support would be valuable treatments to be included with Parkinson's healthcare services.

> “Care pathways need to be created and physiotherapists could take on larger roles to support allied healthcare for Parkinson’s.”
>
> - Geriatrician, Virden, Manitoba

A member of the group who is a person with Parkinson’s and a representative of a Parkinson’s community organization mentioned that their organization offers free programs, such as physiotherapy, as they are aware of the major costs that can act as barriers to receiving treatment. Another member of the group with Parkinson’s also shared their concern with the costs associated with the condition, especially with their retirement years approaching and the worry of losing benefits.

Parkinson’s is an expensive condition and often can result in people unable to work or occurs later in life when people are in their retirement years and no longer have medical benefits from an employer. Living with limited finances and having to pay for services like physiotherapy, exercise, speech therapy, etc. were concerns that were shared by more than one member of the group.

> “The stage you’re at really affects the journey and the care that is needed.”
>
> - Physiotherapist, Winnipeg, Manitoba

There was an overall belief that there needs to be a broader base of better educated and updated professionals in all areas of Parkinson’s. An integrated model of care was raised and while there was a lot of warm reception to the concept, there were also questions raised about what is realistic.

Technology was discussed as to how it can enhance access to care and reduce on travel times and other costs associated with in-person appointments; especially for those living in rural communities. The question was then posed as to what degree could technology offset the need for face-to-face treatments. While many appreciate the conveniences offered through technology, there were doubts with regards to the benefits of movement disorder clinic appointments being virtual and their ability to offer proper assessments.

MODEL OF CARE

When the topic for a model of care was raised, the clinical resource nurse in the group shared that patient education is key. If clients knew a bit more about Parkinson's and its symptoms earlier on, they would be able to identify their needs and who they should contact.

> "Education is so important. The more we learn, the better and the quicker we can advocate for ourselves."
>
> - Person with Parkinson's, Winnipeg, Manitoba

The geriatrician shared that technology has been a useful tool and they have received positive feedback from the experience of telehealth with their patients in rural parts of the province. They went on to say they were impressed with the ability to network and better connect with patients. However, concerns were raised about the reliability of internet connection in some of those small communities.

One of the Parkinson's specialists then shared their belief that telehealth results in faster follow-ups with patients and that they can see more patients on average. It also proves to be superior to a standard phone call. However, there are limitations to telehealth in comparison to what physical appointments can offer. You do not always get an accurate picture with virtual appointments and asking people to describe their symptoms really is not the same as seeing patients in person to assess them properly. Another Parkinson's specialist weighed in and agreed that while telehealth has improved access, it is still better to meet with patients in person.

> "We can see more patients; but don't always get an accurate picture. You can ask all you want about symptoms, but we really do need to see people in person."
>
> - Parkinson's Specialist, Winnipeg, Manitoba

Alternatively, a couple of the group members who live with Parkinson's felt that telehealth was a good experience. It was raised by one individual that their caregiver also benefitted by not needing to take time off work to attend their appointments with them and that it saved them time. A nurse in attendance mentioned that some services, such as speech pathology, could be easily done virtually. It really depends on the healthcare service.

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 [iv, vii]

[ix] Mathematical estimate based on [iv]

The Roundtables and Regional Roundtable Final Reports were supported in part with funding from

abbvie

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