SASKATCHEWAN 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.

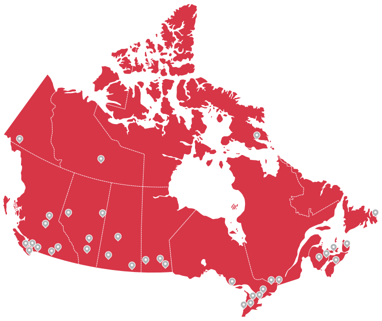
The purpose of the roundtables was to listen to the realities and unmet needs of the Parkinson's community and capture the key issues surrounding Parkinson's healthcare from provincial, territorial, and national perspectives. To support validation of the findings, Parkinson Canada strove for diverse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

It is estimated that there are over 2,500 people in Saskatchewan living with Parkinson's today.[x] Almost every day, a Saskatchewanian is diagnosed with the condition. [iv]

To support this population, there are only three Parkinson's specialists throughout the entire province. [vii] That is one Parkinson's specialist per 853 people living with Parkinson's in Saskatchewan. [viii] The average provincial wait time to see a Parkinson's specialist was eight months in 2018. [vii] Notably, all three specialists are in two major cities within the province, Regina and Saskatoon, posing a geographical challenge for individuals living in more rural areas. Furthermore, more than half of those living with Parkinson's in Saskatchewan report not having access to a neurologist.

On average, out of pocket medication expenses for people in Saskatchewan living with Parkinson's were $350 per year in 2014 and these costs have likely increased. At that time, individuals without coverage paid an average of $1,150 per year.[x] Many express challenges accessing allied healthcare professional services due to a variety of barriers.[x]

An estimated **2,500** people live with Parkinson's in Saskatchewan

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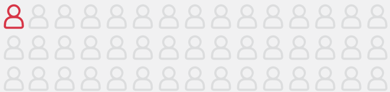
The average provincial wait time was **8 months** to see a Parkinson's specialist in 2018



There is **one** Parkinson's specialist for every **853** people with Parkinson's in the province

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

When participants of the Saskatchewan Roundtable were polled, 88 per cent felt that diagnosis wait times are a challenge in their region. There are three Parkinson's specialists in the province, and all of them are in either Regina or Saskatoon. The distance that some must travel for appointments, plus weather conditions, can act as barriers for those in rural parts of the province. It was suggested that stigma is another issue that can cause delays in receiving a diagnosis.

In some instances, wait times have taken so long that individuals have had to go to other provinces, or into the United States to receive a diagnosis. In contrast, other participants reported a quick diagnosis experience after being referred by their doctor to either a neurologist or Parkinson's specialist.

> "The sooner we can start talking about and naming the condition, the sooner we can start tackling it."
>
> - Person living with Parkinson's, Broderick, Saskatchewan

The challenge with a family doctor can be whether they are educated about the symptoms of Parkinson's and are willing to give a referral to specialized care. A participant of the roundtable, who is a care partner, shared that a lot of the information they received on Parkinson's was through support groups and not through their doctor. Another participant in the group with early onset Parkinson's found that their diagnosis experience took longer because there is still a misconception that Parkinson's is an "older person" condition and may be initially overlooked.

> "Sometimes symptoms will appear for a number of years. You are always aware they are there and thinking 'something is not right', but always pin it on something else. A diagnosis allows you to move forward. You have a name for it."
>
> - Parkinson's care partner, Saskatoon, Saskatchewan

It is important for people to advocate to their doctors for a neurologist referral. There were some participants who believe that an earlier diagnosis, means earlier treatment. The earlier treatment therapies are accessed can significantly relieve the stress of wondering what is happening with your body and what is causing certain health issues to occur. However, there was a shared belief from the group that it is not just about an early diagnosis, so much as having the actual diagnosis itself.

> “Parkinson’s gives you a name for all the symptoms you are experiencing. Before it is hard to put all the pieces together. Education is important.”
>
> - Parkinson Advisory Council member

ACCESS TO CARE

Access to Parkinson’s healthcare professionals is much easier through the hospital. There is a lack of awareness for how to access different healthcare services in the community, or for getting referrals from your doctor. Geography can pose as a barrier for accessing treatment. Many who live in rural parts of the province 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. For those with limited finances, this can be challenging, or even unattainable.

There are services that are not always considered as being essential to the treatment of Parkinson’s. One example is optometry, as the disease can affect vision. Services such as massage therapy and reflexology are not tax deductible for people living with Parkinson’s. Furthermore, exercise programs should be hitting on multiple health concerns – physical, visual, vocal, cognitive, etc. – all at the same time. Often there is someone who specializes in movement, but they do not work on other areas that are also critical to improving movement. In addition, it would be beneficial to have personalized exercise programs, because everyone with Parkinson’s has different needs.

> “Support groups are healthcare services. Many people don’t have any other community contacts or resources available to them. “
>
> - Person living with Parkinson’s, Broderick, Saskatchewan

It was shared by a nurse practitioner who attended that they had received approximately 30 minutes of education in nursing school for Parkinson’s. With the complexity of the disease, it would be beneficial to have more knowledge and understanding to better treat people with Parkinson’s and understand more about their symptoms.

An exercise therapist in attendance who runs a Parkinson exercise program in Saskatoon expressed frustration with the lack of awareness that their program exists. They have tried to get in touch with neurologists in the region to get them to directly refer people who are newly diagnosed to the program. More coordination from healthcare professionals is necessary to get the newly diagnosed the information they need on various support services and treatment options.

MODEL OF CARE

Currently there is no model of care for Parkinson's in Saskatchewan. There was some belief from members in the group that Parkinson's gets "short-changed" in comparison to other diseases, where there are care coordinators available to handle referrals. In addition, any plan for an integrated healthcare model would need to account for geography. For example, an initial assessment would occur in a major city, but then there could be opportunity for follow-up appointments at local clinics for those in rural communities.

> "Other countries have models where a nurse is assigned to someone upon diagnosis to provide education and manage referrals."
>
> - Care partner, Regina, Saskatchewan

The conversation then turned towards telehealth in the age of COVID, as most neurologists were only doing video, or over the phone appointments. While some shared that there are benefits to virtual care (such as prescription renewal), it was still preferred to have the opportunity for in-person appointments.

> "Teleconference can be handy, but there are also times when you need to be in-person."
>
> - Care partner, Saskatoon, Saskatchewan

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

[i i]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]

[x] Chambers-Richards, T., Ahmed, R., & Findlay, I. M. (2014). (rep.). Parkinson Society Saskatchewan: Working Together to Meet Members Needs (pp. 1–95). Saskatoon, SK.

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