



Recommendations to Reduce the Impact of Parkinson's Disease on the B.C. Health System June 2023

Executive Summary:

Parkinson's disease (PD) is the fastest growing and second most common age-related neurodegenerative condition in Canada, just behind Alzheimer's disease. It is progressive and there is no cure. PD patients have a fracture risk approximately twice their peers due to their risk of falls, lower bone mass, and frailty. Up to 27% of patients with PD experience a hip fracture within 10 years of diagnosis. Patients with advanced Parkinson's have limited therapeutic options so often are placed in expensive complex care facilities.

The good news is that with expert and appropriate treatment and access to the latest innovative medications, disease progression can be managed. This results in decreased risk of falls, reduced hospitalizations, and delayed referrals to long-term care. Research demonstrates that well-managed patients can live independently for many years.

More than 15,000 British Columbians live with Parkinson's Disease. Parkinson Society BC (PSBC) recommends the B.C. Government take these five actions to reduce the impact of Parkinson's Disease on the B.C. health-care system.

- 1. Maintain and expand specialized staff in existing health authority PD programs.**
- 2. Create new opportunities to train health professionals to support patients with PD.**
- 3. Provide timely access to new innovative medications.**
- 4. Expand access to Deep Brain Stimulation as required to ensure timely access.**
- 5. Increase and standardize funding for home care and respite.**

Recommendations:

- 1. Maintain and expand specialized allied health care staff in existing health authority PD programs.**

Managing disease progression requires a specialized, team-based approach to healthcare. In addition to neurologists who are movement disorder specialists, other health care staff including physiotherapists, speech-language pathologists, occupational therapists, social workers, and exercise professionals all help contribute to additional years of patient independence. Many of these staff work together in Movement Disorder Clinics or other health authority PD programs located around the province. Long waitlists or even no access to these critical services will often lead to unnecessary disease progression.

Following a lack of access to these specialized staff, PSBC in 2020 committed to invest \$1.5 million over five years across three health authorities to provide access to these critical services in Movement Disorder Clinics

in Vancouver, Victoria and Kelowna. An additional \$500,000 has been committed to the new clinic in Nanaimo. The funding agreements stipulated that the health authorities would continue the funding at the end of this term.

PSBC is a small non-profit and is unable to commit to continuing this support. We therefore ask the B.C. government to work with the health authorities to sustain and increase the allied health care staff in these Movement Disorder clinics.

2. Create new opportunities to train health professionals to support patients with PD.

Research shows that people who receive skilled care are at a lower risk of complications and have a better quality of life. Ensuring additional members of a patient's care team have appropriate expertise can maximise the quality of life for those living with Parkinson's disease and help manage disease progression.

To help increase access to these skilled health care staff, PSBC has trained over 180 physiotherapists, kinesiologists, occupational therapist and certified exercise professionals in Parkinson's specific therapies and exercises. We also offer six \$1000 scholarships annually for these professionals and others such as speech language therapists to partake in Parkinson's specific training for their profession.

However, more needs to be done and we ask the B.C Government to create new training opportunities or help PSBC increase access to its programs.

3. Provide timely access to new medications.

While there is currently no cure for Parkinson's, medications can often provide good symptom control for a long time. Since many of the motor symptoms of Parkinson's are the result of a lack of dopamine in the brain, most drugs used to treat Parkinson's are aimed at temporarily replenishing or imitating dopamine.

Several classes of medications are available but Levodopa remains the most effective treatment and is available in many strengths and formulations. It also may be used in combination with other classes of medications. Treatment is highly individualized and adjusted over time based on symptoms and side effects.

Some patients with advanced Parkinson's Disease whose symptoms can't be controlled through tablets benefit from a gel form of levodopa which is delivered through a tube surgically inserted into the intestine. Newer versions which deliver the gel continuously under the skin could also benefit some patients.

Access to appropriate medications and therapies can help keep people with PD independent and assist with activities most of us take for granted such as movement and the ability to speak and swallow. The alternative is grim: increased risk of falls and choking, reduced communication, being confined to bed, and ultimately placement in expensive complex care facilities.

PSBC requests that the B.C. Government commit to provide timely access to new therapies that demonstrate benefits for PD patients.

4. Expand access to Deep Brain Stimulation as required to ensure timely access.

Deep Brain Stimulation (DBS) is a neurosurgical procedure that uses implanted electrodes and electrical stimulation to treat PD and other movement disorders. Patients are typically eligible when medications to control motor function are ineffective. Benefits of DBS can include fewer tremors, improved facial expression and reductions in medication.

In 2019, the B.C. Government announced additional funding to double the number of surgeries performed annually from 36 to 72 but patients can still wait years to access this critical procedure performed by only one surgeon in the province. Currently, patients are waiting up to 5 years. Government also funded the recruitment of a second qualified neurosurgeon who has now been recruited. To assist with increasing qualified neurosurgeons, PSBC provided the funding for this physician's training in stereotactical surgery.

However, even with two neurosurgeons performing DBS, British Columbia will still fall behind other provinces which have one qualified DBS neurosurgeon for every 1 million people. We encourage BC to monitor wait times and consider additional resources which may be required to ensure timely access to this very valuable surgery.

5. Increase and standardize funding for home care and respite.

Providing supports such as home care and respite can make a difference in a care partner's ability to continue to care for the person with PD. Failing health of the care partner often results in more frequent use of emergency services and acute care and a faster transition to complex care for the person with PD. The type of care available depends upon where you live and standards of care are inequitable across the province. We therefore request the B.C. Government expand these supports and ensure the services are standardized around the province.

Even when the services are in place, identifying and accessing them can be a challenge. For this reason, PSBC provides a healthcare navigator service to assist people with PD and their care partners. This service is impactful and is driving better health outcomes. However, it is insufficient and we ask the B.C. Government to partner with us to expand this important service.

Appendix A: Parkinson Society Overview

Established in 1969, Parkinson Society British Columbia is a non-profit organization governed by a volunteer Board of Directors. The Society is supported entirely by donations from individuals, members, corporations, foundations, and the dedicated efforts of volunteers. We believe that every person touched by Parkinson's deserves to know that they are not alone in their journey

The Society has a strong volunteer presence throughout the province with 50 support groups in various communities. These groups provide education and support to their members as well as fund raising to support the work of the Society. The Society provides regional educational conferences in larger communities as well as community talks in others. They also provide communication and swallowing workshops as needed, have a free counselling service available by phone delivered by a registered clinical counsellor, and provide webinars on a regular basis.

Investments PSBC has made in funding for staffing and training:

- The Society is providing \$2 million over five years to three of the health authorities – Interior (2020 – 2025), Island (2020- 2025 and 2023- 2028) and Vancouver (2022- 2027) – to support the recruitment of specialized staff in their Movement Disorder clinics to provide improved care
- The Society has trained at least 180 physiotherapists, occupational therapists, kinesiologists and exercise professionals in Parkinson's specific therapies and exercise techniques.
- The Society has also provided six annual scholarships of \$1000 each since 2015 to the above professionals and also to speech therapists to improve their knowledge and expertise in Parkinson's therapy and care.
- PSBC provided the funding for Dr. Stephan Lang's training in stereotactical surgery (Deep Brain Stimulation or DBS). Vancouver Coastal recently recruited him as BC's 2nd Deep Brain Stimulation neurosurgeon.
- PSBC provided the funding for training of two Movement Disorder specialists now employed in BC Movement Disorder clinics – Dr. Daryl Wile in Kelowna and Dr. Anis Kanungo in Surrey.
- PSBC provides clinical counselling, free of charge to people with Parkinson's and their care providers. Some of the non-motor issues of PD are depression, anxiety and depression caused but the chemical changes in the brain. Counselling along with appropriate medication can assist with these issues.
- PSBC provides health care navigation service to people with Parkinson's and their care providers. Accessing aspects of the formal healthcare system is complex. As people with PD and their care partners age, navigating the system becomes increasingly complex at a time when they require these services even more.

As a relatively small charity (\$610,000 in 2022 revenue), PSBC is very proud of what we have been able to accomplish with donor funds. Going forward, we need government to assist to ensure these investments will be sustained and to assist with providing further funding for these initiatives.

Appendix B: Impact of the Disease - Case for Action

- People with Parkinson's disease are *admitted to the hospital 50 percent more often than their peers*. Once admitted, they typically stay in the hospital for longer.
- Parkinson's disease (PD) is the second most common neurological disease after Alzheimer's.
- Parkinson's has the **third highest level of direct healthcare costs for neurological disease**, after Alzheimer's disease and Epilepsy.
- In 2015/16, the BC Ministry of Health estimated that **\$123 million** was spent on direct care related to PD including hospital, MSP, and PharmaCare costs. In 2012/2013, they estimated that **\$112 million** was spent on direct care related to PD including hospital, MSP, and Pharmacare costs. This represents a 9% increase in costs over three years. The estimated cost in 2000-2001 was \$45 million.
- BC's Ministry of Health data indicates the number of Parkinson's patients in BC has increased by 31% from around 8,700 in 2001-02 to 12,600 in 2015-16. In the next five years to 2020,21, a further increase of 18% to 15, 324 has occurred.
- The number of people with PD is expected to double by 2031; as a result, projected costs would double to **\$246 million** by 2031.
- Payback through controlling costs:
 - Research shows that Parkinson's patient outcomes improve with regular access to specialized care.
 - Admissions to hospital and long-term care are reduced.
- If even fifty people with Parkinson's can be better served by this multidisciplinary approach, a cost avoidance of a conservative \$4 million can be reached (based on an average cost of \$80,000 per LTC bed x 50 people per year. Cost for a hospital bed is \$400 to \$1,100 or average of \$750/day x 50 patients= \$37,500 per day).
- In a May 2019 survey of our Parkinson's community, where we asked people about their access to allied health services, of the 400 respondents with Parkinson's disease, access issues were indicated as follows:
 - 68.12% indicated that they had not seen a speech-language therapist.
 - 41.46% indicated that they had not seen a physiotherapist.
 - 78.24% indicated that they had not seen a social worker.
 - 39.04% indicated that they have had difficulty paying out-of-pocket to visit allied healthcare professionals.

Appendix C: The role various specialized staff play supporting PD patients.

The value of a trained multidisciplinary team lies in delivering comprehensive care to people with PD, allowing people to live independently in the community longer, and reducing hospital admissions and residential care admissions of patients and caregivers.

Movement Disorder Specialist - These are neurologists who have completed two years of extra training (a fellowship) in movement disorders, a subspecialty in neurology. With this level of experience, a movement disorders specialist is more familiar with the range of available PD medications, how they work, and their possible side effects. Movement disorder specialists are more likely to be aware of which healthcare professionals may be helpful with day-to-day challenges. These professionals may include physical therapists, occupational therapists, speech therapists and nutritionists.

Physiotherapist: The key aims of physiotherapy in Parkinson's are to maintain and improve functional ability and independence, to correct and improve posture and balance and to minimize the risk of falls.

Speech-language pathologist: helps with maintaining as many communication skills as possible. Teaches techniques to conserve energy, including using nonverbal communication skills. Introduces assistive devices and techniques to help improve communication.

Occupational therapist: supports the patient and helps them maintain their usual level of self-care, work, and leisure activities for as long as possible. When it is no longer possible to maintain their usual activities, occupational therapists support individuals in changing and adapting their relationship with their physical and social environment to develop new valued activities and roles.

Social workers: help people with Parkinson's and their families navigate the health care system and work through disease transitions.

Exercise professionals: provide leadership, expertise, and programs to help people living with Parkinson's achieve their goals and manage their Parkinson's symptoms. Physical activity also slows the disease process, decreases the pain associated with Parkinson's disease, prolongs the independent mobility (gait, balance, strength) and improves sleep, mood, memory hence improving the overall quality of life.

Appendix D: Additional detail supporting the request to maintain and expand specialized staff working in health authorities in existing PD programs.

Following a steady increase in wait times to access these specialized staff, PSBC in 2019 committed to invest \$1.5 million over five years across three health authorities to help reduce waitlists to these critical services in Movement Disorder Clinics in Vancouver, Surrey, Victoria, and Kelowna <CHECK>. An additional \$500,000 has been committed to the new clinic in Nanaimo. The funding agreements stipulated that the health authorities would continue the funding at the end of this term.

PSBC is a small non-profit and is unable to commit to continuing this support. We therefore ask the B.C. government to work with the health authorities to sustain and increase these allied health care staff in these Movement Disorder clinics.

Priority One: Okanagan Movement Disorder Clinic, Kelowna

Of the 15,000 British Columbians with Parkinson's disease (PD), 2,694 reside in Interior Health Authority Region and, of these, 1,516 live close to Kelowna (Appendix C). The Central Okanagan is the health sub-region with the second highest crude prevalence rate of Parkinsonism in the province after Fraser Health East (Appendix B), with approximately 17% increase in the past 5 years.

Dr. Daryl Wile was hired in July 2015 and started the Okanagan Movement Disorder Clinic (www.okmove.ca) aiming to provide comprehensive multidisciplinary care, advanced therapies, and research for patients in the Okanagan with Parkinson's disease and other movement disorders. The Kelowna clinic was provided a part-time nurse but with a growing waitlist, this clinic was and continues to be a priority.

The mandate of the clinic is centered upon empowering patients to be physically active as this is the best-known means of slowing disease progression. Currently, there are three clinic days per week, two which are supported by skilled nursing care with additional administrative support three days per week. There have been approximately 2,000 movement disorder patient visits in that time, and the community continues to express a high referral rate. Dedicated access to physiotherapy, speech language therapy, and a social worker was needed.

Given this focus, Parkinson Society British Columbia (PSBC) offered funding for allied health staff for a period of 5 years (June 2020 through March 2025) with transition to the Interior Health Authority's base budget during years 4 and 5. Provincial funding needs to be supplied to the Health Authority 2023 forward.

Priority Two: Movement Disorder Clinic, Victoria

Vancouver Island Health Authority hired its first neurologist with a movement disorder specialty in May 2019. Allied health professionals are required to support patients in this burgeoning new clinic.

Vancouver Island has a similar Parkinson's disease prevalence to Interior Health with 3,067 patients with approximately half, 1508, residing in the southern Island. A multidisciplinary approach benefits patients and reduces overall healthcare costs. The clinic and Health Authority requested Parkinson Society BC fund a fulltime speech therapist and a five year contract for funding has been provided. Provincial funding needs to be supplied to the Health Authority 2023 forward.

Priority Three: Movement Disorder Clinic, UBC Vancouver

The UBC Clinic was the first one in BC and has seen growth in the number of Movement Disorder specialists. However, building the team of allied healthcare professionals has been challenging. Therefore, PSBC also entered into a contract in 2022 to fund a part-time Occupational Therapist and part-time speech therapist.

A five year contract for funding has also been provided to Vancouver Coastal Health Authority. Provincial funding needs to be supplied to the Health Authority 2026 forward.

Priority Four: Movement Disorder Clinic, Nanaimo

A Movement Disorder Clinic opened in fall of 2021 with a neurologist specializing in Movement Disorders and no other staff. The prevalence of Parkinson's disease in the mid to northern Island equals that of the Victoria area with 1559 patients. Subsequently, PSBC offered five-year funding for allied healthcare staff and recruiting for a fulltime speech therapist is underway.

Priority Five: Visiting Clinics for More Remote Communities

People in communities such as Prince George, Quesnel and Terrace must travel considerable distances at their own expense to access necessary care. Although the population may be insufficient for healthcare experts to reside in their communities (595), the number of patients is sufficient to enable visiting clinics with healthcare providers. PSBC is currently facilitating discussions with Northern Health and Movement Disorder specialists from the UBC Clinic.

Priority Five: Fraser Valley/Abbotsford East

People in the Fraser Valley are currently served by the James Pattison Neurology Clinic in Surrey. The clinic does provide a multidisciplinary service but has a growing waitlist. In addition, the Parkinson's population of 5354 is the greatest in the province and prevalence has increased by 21% from 2015/16 to 2020/21. For several years, patients have been asking for a movement disorder specialist based in Abbotsford to enable more accessible care.