



Five Point Plan for Enhanced Support for Parkinson's Disease In B.C.

October 13, 2017

Executive Summary

More than 13,300 British Columbians live with Parkinson's Disease (PD); our aging population means this number will only increase. While treatment is complex, it is one of the most treatable neurological conditions. With expert and appropriate treatment and therapies, disease progression can be managed with decreased risk of falls, hospitalizations and referrals to long term care. Many patients who are well managed are able to live independently for many years.

While expert supports are available in the province, long waitlists often lead to delayed treatment and unnecessary disease progression. Once patients do receive care, allied health professionals often lack knowledge of PD and best practices for disease management, leading patients to often receive improper treatment in emergency rooms, hospitals, general practices, and care homes. And patients with advanced Parkinson's have limited therapeutic options so that often the only option is placement in expensive complex care facilities.

PSBC Five Point Plan

1. Add specialized staff to existing PD programs

- Add physicians and allied health professionals to allow additional and timely assessment capacity at PD specific treatment programs in the province. Patients currently can face an 18-24 month wait during which their condition continues to deteriorate.

2. Fund PD specific training for allied health professionals

- People living with PD regularly use physio services to maintain movement but very few of the province's 3,500 physiotherapists have training related to PD and movement disorders.
- The situation is similar for other allied health professionals such as speech language pathologists and occupational therapists.

3. Expand the Deep Brain Stimulation program

- This is an option for a small number of patients with advanced PD. The surgery has enabled people to live independently in their own homes for many more years.
- However, patients can wait up to five years for surgery, given funding limits. As PD is progressive, patients may no longer fit the criteria for surgery after waiting so long.

4. Expand medication coverage

- Access to appropriate medications can help keep people with PD independent, assisting with activities of daily living that most of us take for granted such as mobility and the ability to speak and swallow. The alternative is grim: increased risk of falls, being confined to bed, reduced communication and increased risk of choking.

- In a June 2017 PSBC survey with 400 respondents, 17% reported either sometimes or always having difficulty with paying out of pocket costs for medication.

5. Support for Care Partners

- Results from the PSBC survey indicate that the majority of Care Partners of people with PD were spouses, female, retired and lived with the person they cared for. 28% indicated responsibilities of caregiving affected emotions such as anger, resentment, depression and anxiety which had a negative impact on quality of life and a loss of freedom.
- Failing health of the care partner usually results in the person with PD transitioning to residential sooner than necessary and/or more frequent use of emergency services and acute care.
- Providing support such as home care and respite can make a difference in the care partner's ability to continue to care for the person with PD.

By taking action in these areas the province can help those with PD lead independent lives as long as possible and reduce their overall impact on the healthcare system.

Expected Benefits

- A cost avoidance of a conservative \$4 million (based on an average cost of \$80,000 per LTC bed x 50 people per year. Cost for a hospital bed is \$400 to \$1100 or \$33,000 per day).
- 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.
 - Parkinson's disease (PD) is the second most common neurological disease after Alzheimer's.
 - Parkinson's has the **third highest level of direct health care costs for neurological disease**, after Alzheimer's disease and Epilepsy.
 - In 2012/2013, the BC Ministry of Health estimated that **\$112 million** was spent on direct care related to PD including hospital, MSP, and Pharmacare costs. 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 39% in the last decade from around 8,600 in 2001-02 to 13,300 in 2013-14.
 - The number of people with PD is expected to roughly double by 2031; as a result, costs can be projected to double to **\$224 million** by 2031.

What is PD?

Parkinson's disease is a degenerative neurological condition which affects one in every 500 people. Here in BC approximately 13,300 British Columbians live with the disease. Symptoms include tremors, loss of balance, and difficulty with movement and fine motor skills. Parkinson is progressive, meaning the symptoms generally worsen over time though the rate of progression is different for each person.

Many people are able to control their symptoms for several years through oral therapies including levodopa. However some patients progress to advanced Parkinson's and have severe, disabling motor fluctuations and hyper-/dyskinesia (involuntary movements) which can no longer be controlled by combinations of available oral medicinal products for Parkinson's disease

Increasing Prevalence

Demographic trends indicate that British Columbia, along with the rest of Canada, is experiencing significant population aging. The chance of developing Parkinson's disease increases significantly with age.

- The average age that people get PD is 62. Early Onset occurs in about 5 to 10% and occurs as early as people in their 40's.
- 85% of those diagnosed with Parkinson's are over the age of 65 and that age group is predicted to double over the next 30 years from 11.6% to 23.6% of the population
- Currently around 12% of Canada's over 80 population lives with Parkinson's Disease.

Current barriers to the proper management of PD:

- Lack of integration in the system; disconnect between PD specialists and general health care providers.
- Waitlists of up to 24 months to see a specialist.
- No PD specialists in senior populated centres such as Victoria and Abbotsford and insufficient allied health professionals in centres such as Kelowna
- Allied health professionals often lack knowledge of PD and its management, leading patients to often receive improper treatment in emergency rooms, hospitals, general practices, and care homes.
- Deep Brain Stimulation program is under resourced both for access to the procedure and follow up with those who have received it.

Why is the proper management of PD important?

The treatment of PD is *complex*. However, it is one of the *most treatable* neurological conditions; but the specific medication types, combinations, timing and dosage are all crucial for proper patient functioning and quality of life. There are no objective diagnostic criteria for PD, so a comprehensive neurological examination is required.

If treatment is inappropriate, patients are at higher risk of falls, hospitalization, increased length of hospital stays, slower recovery from illness or surgery, and faster disease progression. *The difference between optimal versus ineffective therapy may be the difference between hospitalization, a nursing home or independent living.*

PSBC Action Plan Point One: Add specialized staff to existing PD clinics and provide specialized staff in additional communities where access is difficult

Annual funding to enable the hiring of additional staff at the UBC Movement Disorder Clinic (\$100,000), hiring and housing of Movement Disorder specialists in Victoria and Abbotsford (\$500,000), and additional staff in Kelowna (\$200,000).

Why?

- People with Parkinson’s disease are **admitted to the hospital 50 percent more** than their peers. And, once admitted, typically have **longer hospital stays**.
- Parkinson’s has the **third highest level of direct health care costs for a neurological disease**, after Alzheimer’s disease and other dementias and Epilepsy.
- People living with Parkinson’s disease have the **highest use of prescription medication**.
- Patterns of **use of emergency room visits and hospitalizations** suggest that unless a patient with Parkinson’s is under the care of a Movement Disorder specialist, their **overall condition will worsen and length of stay will increase**. This is due to an overall lack of understanding and of the need for Parkinson’s disease patients to be kept on a strict schedule with their medication.
- Waitlists will continue to increase without increasing funding for staffing for specialized care at the Movement Disorder Clinics.

How will this help?

The value of a trained multidisciplinary team (nurse, physio, occupational therapist, speech language pathologist and social worker) is in delivering comprehensive care to people with PD, allowing people to live independently in the community longer and reducing hospital admissions of the patients and caregivers as well as premature residential care admissions. Allied health professionals are essential in supporting the movement disorder neurologists to deliver quality care to people living with PD in accordance with the **Canadian Guidelines for Parkinson's Disease**.

Research shows that patients treated at a Clinic for Movement Disorders have:

- Reduced lengths of hospital stays.
- Reduced long-term care admissions.
- Fewer unnecessary visits to neurologists.

Reducing Waitlists

Until recently, the **Movement Disorder Clinic**, UBC Vancouver Campus, was the only specialty clinic for all of BC. Numbers of new referrals increased by 40-50% from 2006 to 2012 and has continued at this higher rate. New patients need to be scheduled as well as existing patients. Life expectancy for someone with PD is about the same as for people without the disease, so treatment can go on for many years. The UBC Clinic has an intake of ten new complex patients seen every week. Most require follow up on a long term basis further increasing the waitlist for new referrals.

The number of physicians, allied health positions and public funding for the clinic has not grown in the last ten years. Currently, people with PD in British Columbia face a very lengthy waitlist – 18 to 24 months at UBC – to see a Movement Disorder specialist.

NEW REFERRALS - Movement Disorder Clinic, UBC											
year	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
# of new referrals	809	862	917	926	970	1016	1334	1128	974	1732	1025

The **Jim Pattison Outpatient Care and Surgery Centre** in Surrey has two Movement Disorder specialists. They have 740 patients waiting to be booked in to be seen. Some are waiting up to 18 months to be seen. This is an increase from 2015 when 50 to 100 patients were on the waitlist at any given time with a wait time of 6 months. In 2012/13, the BC Ministry of Health estimated a prevalence of 3,902 cases in the Fraser Health Region.

The **Okanagan Movement Disorders Clinic** has operated with one movement disorders neurologist and a part-time nurse since August 2015, with a capacity for approximately 300 patient appointments per year. In 2012/13, the BC Ministry of Health estimated a prevalence of 2,270 Parkinson's disease cases in the Interior Health Region. As of August 2017, the waitlist for this clinic is at approximately 300 patients.

The biggest limiting factor for Movement Disorder specialists is time. Competing demands include balancing clinical workload with research, neurology coverage at hospitals and administrative work. Additional neurologists have a major impact on addressing these issues.

The second biggest factor can be space and resources available which limits the amount of time in clinic.

Valuable help are the nurses who field patient calls, do assessments, and coordinate treatment. However, these nurses are often part time or there are not enough for the patient load and are stretched to the limits for time.

Other helpful allied health staff include physiotherapists with expertise in PD and Speech Language Pathologists with expertise in PD. Patients still do not have easy or timely access to these key disciplines. Further to this, dietetics and social work are often needed.

Close interaction and learning is maintained between the staff in the various clinics. Staff in Kelowna and Surrey received some of their Parkinson's disease training through the UBC clinic, Vancouver.

PSBC Action Plan Point Two: Fund PD specific training for allied health professionals

- People living with PD regularly use physio services to maintain movement but very few of the province's 3,500 physiotherapists have training related to PD and movement disorders.
- The situation is similar for other allied health professionals such as speech language pathologists and occupational therapists.
- In 2016, PSBC partnered with UBC Continuing Medical Education to develop a proposed program to train physiotherapists in Parkinson's disease; however, funding was not available to proceed,
- There is interest from other health professionals in developing continuing education programs for them as well but funding is required.

UBC CME's proposal for Continuing Education of Physiotherapists: After the initial investment of \$115,000, this program will be operated on a cost recovery model. With additional funding, this continuing education could be expanded to address the education needs of other health professionals.

Why is this needed? And how will this help?

The value of a trained multidisciplinary team (nurse, physio, occupational therapist, speech language pathologist and social worker) is in delivering comprehensive care to people with PD, allowing people to live independently in the community longer and reducing hospital admissions of the patients and caregivers as well as premature residential care admissions. Allied health professionals are essential in supporting the movement disorder neurologists to deliver quality care to people living with PD in accordance with the *Canadian Guidelines for Parkinson's Disease*.

For physiotherapists, this initiative is especially important given the recent research on the efficacy of physical activity in assisting with symptom control and delay of the progression of Parkinson's disease. As rigidity and balance issues have to be managed, physiotherapy is essential in getting people with Parkinson's mobile, safely and effectively and in providing support as the disease progresses. Appropriate physiotherapy assists in the prevention of falls, one of the most common reasons for hospitalization.

There are approximately 3,560 physiotherapists in BC. People living with PD and their care partners regularly use physio services. Despite the regular use of services, only a small number of physiotherapists have post-graduate continuing education related to PD and movement disorders. An even smaller number of physiotherapists specialise in providing care for people with PD.

UBC Continuing Medical Education (CME) partnered with PSBC in developing a proposal for the provision of education in Parkinson's disease to BC physiotherapists. The full proposal is available upon request.

This proposal has potential for being broadened to include introductory material applicable to all disciplines with follow up modules discipline specific.

PSBC Action Plan Point Three: Expand the Deep Brain Stimulation program

Why?

Deep brain stimulation (DBS) is a surgical procedure used to treat a variety of disabling neurological symptoms—most commonly the debilitating symptoms of Parkinson’s disease (PD), such as tremor, rigidity, stiffness, slowed movement, and walking problems.

At present, the procedure is used only for patients whose symptoms cannot be adequately controlled with medications. DBS uses a surgically implanted, battery-operated medical device called a neurostimulator—similar to a heart pacemaker and approximately the size of a stopwatch—to deliver electrical stimulation to targeted areas in the brain that control movement, blocking the abnormal nerve signals that cause tremor and PD symptoms.

Currently only Dr. Chris Honey is trained to do this procedure in BC. In comparison, Alberta, with a smaller population, has three DBS neurosurgeons, one in Calgary and two in Edmonton. Waitlist for this procedure can be up to four years in BC. In Alberta, the waitlist is several months. Funding for additional surgeries is needed as well as the follow up with existing patients.

How will this help?

The surgery has enabled people to live independently in their own homes for many more years. For a young person, it has allowed them to get off of disability and go back to work and pay taxes once again. For the older patient, it enables a care giving spouse to be released from the caregiver role, improve their own health and, if still of working age, become re-employed. For the older person, life at home continues instead of becoming so disabled that long term care is required and possible hospitalization as they wait for a space.

PSBC Action Plan Point Four: Expand medication coverage

Why?

In a June 2017 PSBC survey with 400 respondents, 17% reported either sometimes or always having difficulty with paying out of pocket costs for medication.

A number of Parkinson’s medications, although covered in other provinces by ministries of health, are not covered in BC – see Appendix A.

How will this help?

Access to appropriate medications can help keep people with PD independent, assisting with activities of daily living that most of us take for granted such as mobility and the ability to speak and swallow. The alternative is grim: increased risk of falls, being confined to bed, reduced communication and increased risk of choking.

PSBC Action Plan Point Five: Support for Care Partners

Why?

Results from the June 2017 PSBC survey indicate that the majority of care partners of people with PD were spouses, female, retired and lived with the person they cared for. 28% indicated responsibilities of caregiving affected emotions such as anger, resentment, depression and anxiety which had a negative impact on quality of life and a loss of freedom.

Failing health of the care partner results in the person with PD transitioning to residential sooner than necessary and/or more frequent use of emergency services and acute care.

How will this help?

Providing support such as home care and respite can make a difference in the care partner's ability to continue to care for the person with PD.

More indepth information and recommendations can be found in the *Caregivers in Distress* August 2017 report from the Office of the Seniors Advocate BC:

http://surveybcseniors.org/assets/media/caregivers_in_Distress_-_a_growing_problem_-_final.pdf

Appendix A: MEDICATIONS TO TREAT PARKINSON'S DISEASE (PD) AND NOT COVERED BY BC PHARMACARE

1. **Levodopa (Dopamine precursor)** – dopamine cannot cross the blood-brain barrier. When administered peripherally, it produces adverse effects such as nausea and dizziness and is not effective in controlling symptoms of PD. Levodopa is a dopamine precursor that can cross the blood-brain barrier but as it is rapidly broken down, large doses are needed to produce an effect on motor symptoms of PD. Inhibitors are given concurrently with levodopa to prevent its breakdown in the periphery, allowing levodopa to cross the blood-brain barrier.

“Sinemet CR” preparations (CR — controlled release) has a coating on it which slows absorption. In some generics, although the active ingredient inside may be the same, the coating may not be, significantly affecting the therapeutic response. The brand name is only covered to the same level as generics and some people with PD do not find the generics as effective.

Parkinson's Society BC (PSBC) requests that after failure on a generic, the brand name drug, Sinemet, be totally covered by BC Pharmacare.

2. **Dopamine agonists** – synthetic agents that simulate dopamine's action in the brain

Pramipexole, ropinirole and rotogotine patch - without needing to first “fail” bromocriptine.

Bromocriptine is an ergot Derivative and should not be considered as the dopamine agonist of first choice. Pramipexole, ropinirole and rotogotine patch are preferred to bromocriptine because of the risk of serious pulmonary or cardiac valve fibrosis.

Pramipexole, ropinirole and rotogotine patch are all covered in other provinces. They are currently only available in BC through Special Authority and only after a patient has 'failed' on bromocriptine.

Of note, bromocriptine is four times the price of pramipexole and ropinirole.

Although the rotogotine patch is expensive, it should be covered for adjunctive therapy to levodopa for the treatment of patients with advanced stage Parkinson's disease. It can make the difference between mobility, ability to speak, eat and carry out activities of daily living or being confined to a hospital bed without capacity to move, speak or eat.

PSBC requests that pramipexole and ropinirole be covered by BC Pharmacare without Special Authority and the requirement to first fail on bromocriptine be removed.

3. **MAO-B Inhibitors** – prevent the metabolism of dopamine in the brain by inhibiting the action of the enzyme monoamine oxidase B. This results in increased amounts of dopamine in the brain.

Rasagiline - covered in other provinces and now off patent

PSBC requests that rasagiline be covered by BC Pharmacare.

Appendix B: More About PD

PD's Progression

Although PD can be a frightening diagnosis, life expectancy is about the same as for people without the disease. For some people, symptoms evolve slowly over 20 years. Early treatment can provide years that are virtually symptom-free. As the disease progresses, it becomes increasingly difficult to treat and often requires several different medications, each with its own specific dosage and schedule. The consequences of inappropriate treatment can be especially serious for more advanced patients.

About 5 to 10% of cases occur before age 50. Famous examples are: Boxer Muhammad Ali at age 42 and actor Michael J. Fox at age 30.

Who Gets PD?

Although the average age that people get PD is 62, people over 60 have only a 2 to 4% chance of getting the disease. Having a family member with PD slightly increases your risk. Men are more likely to have PD than women.

What Causes PD symptoms?

A small area in the brain stem called the substantia nigra controls movement. In PD, cells in the substantia nigra stop making dopamine and die, a brain chemical that helps nerve cells communicate. As these dopamine making cells die, the brain does not receive the necessary messages about how and when to move.

How is PD Diagnosed?

There are no lab tests that can diagnose Parkinson's. A diagnosis of Parkinson's disease is based on medical history and a thorough neurological exam. In some cases, the doctor will have the patient try Levodopa treatment. If Levodopa helps alleviate the PD symptoms, it typically means that the accurate diagnosis has been made.

Treatment: Levodopa

Levodopa (L-dopa) is a drug that the brain converts into dopamine. It has been used since the 1970's and is still the most effective PD medication. It reduces bradykinesia and rigidity, helping people to move more easily. Eventually, levodopa may wear off quickly. It should not be taken with a high-protein diet. Common side effects are nausea, vomiting and drowsiness.

Cost Effective:

A five-year study conducted by Institute for Clinical and Evaluative Studies (ICES) found that patients treated at the Clinic for Movement Disorders (Markham, Ontario) demonstrated:

- Reduced lengths of hospital stays to 14.09 days per CFMD patient compared to an average 17.17 days per patient for the non-CFMD cohort.
- Reduced long-term care admissions by 10% compared to other patients in Ontario.
- More access to patient-centred support care means fewer unnecessary visits to neurologists.

Parkinson's disease (PD) is one of the most treatable of all neurological conditions. Medical treatment increases longevity and allows most people with PD to remain active and productive for many years.

However, the medical treatment of PD, is not always simple. The choice of drug, dose and timing are crucial. Motor and non-motor symptoms must be treated and the need for specialist care increases with the advancing disease. The difference between optimal versus ineffective therapy may be the difference between a nursing home and independent living.

Because of the complexity of this disease, general practitioners often find it difficult to diagnose and then to treat. They may refer patients to either a community neurologist who specializes in a variety of neurological conditions or to a neurologist who specializes in Movement Disorders.

Advanced Parkinson's Disease

Deep brain stimulation (DBS) is a surgical procedure used to treat a variety of disabling neurological symptoms—most commonly the debilitating symptoms of Parkinson's disease (PD), such as tremor, rigidity, stiffness, slowed movement, and walking problems. At present, the procedure is used only for patients whose symptoms cannot be adequately controlled with medications. DBS uses a surgically implanted, battery-operated medical device called a neurostimulator—similar to a heart pacemaker and approximately the size of a stopwatch—to deliver electrical stimulation to targeted areas in the brain that control movement, blocking the abnormal nerve signals that cause tremor and PD symptoms.

DUODOPA® is a levodopa and carbidopa combination in the form of a gel that is delivered directly into the small intestine. This type of treatment is for use in patients with advanced Parkinson's disease who have severe and disabling motor symptoms that cannot be well controlled with available combinations of medications for Parkinson's disease.

The gel is delivered continuously throughout the day with a pump via a tube, directly into the small intestine to provide more constant amounts of levodopa and carbidopa in the body throughout the day.

Parkinson's Society British Columbia

Established in 1969, Parkinson Society British Columbia, governed by a voluntary [Board of Directors](#), receives no government funding and is supported entirely by donations from individuals, members, corporations, foundations and the dedicated efforts of volunteers.

Our friendly and knowledgeable staff is committed to offering support, sharing reliable information and providing education for people with Parkinson's, caregivers and healthcare professionals.

PSBC's support services include:

- Counselling – available by phone or in-person
- Consultations – available by phone, Email or in-person; toll-free information line – 1-800-668-3330
- Resources and community referrals – available on line and in print
- Support Groups – we have a network of 50 groups across BC
- PD Link –a peer program connecting individuals with Parkinson's and caregivers on a one-to-one basis for support
- Education events – providing support and learning opportunities
- Exercise programs – development of and referral to community resources; Education for health professionals including training in Parkinson's specific therapy and exercise for Physios, Occupational Therapists and exercise professionals