



# VIEWPOINTS

## Summer 2023

### VIEWPOINTS

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by Parkinson Society  
British Columbia

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## Your support is essential.

Parkinson Society BC would not exist without the support of our members, donors, and volunteers.

## OUR MISSION

Parkinson Society British Columbia exists to empower people with Parkinson's in British Columbia through providing resources and services to enable self-management, self-reliance, and self-advocacy.

## Here are a few of the ways you can support the Society:

### MEMBERSHIP

For an annual fee of \$25, your household benefits from unlimited access to our education and support services, events, and resources.

### DONATIONS

Contact us to set up monthly, quarterly or annual donations, or think of us when giving through United Way.

### PLANNED GIVING & BEQUESTS

Consider Parkinson Society British Columbia as a beneficiary in your will.

### FUNDRAISING

Become a Champion for Parkinson's by organizing your own event benefiting the Society. For more information on how you can support us, visit [www.parkinson.bc.ca/donate](http://www.parkinson.bc.ca/donate).

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Articles contained in Viewpoints are for information only. Parkinson Society British Columbia does not guarantee nor endorse any product or claim made by an author. In matters of medical treatment or therapy, patients should consult their physicians.

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# Ask an Expert

## How the Healthcare Navigator service at Parkinson Society BC can connect people touched by Parkinson's disease with healthcare resources and social services



**Jennifer Allen** is a Registered Social Worker (RSW) with a Master of Social Work (MSW) from the University of British Columbia, and a member of the BC Association

of Social Workers. She has been involved in neurological rehabilitation for 25 years and has worked in a variety of healthcare settings. Jennifer has specialized skills and knowledge about the psychosocial aspects of neurological rehabilitation, particularly traumatic brain injury, concussion, stroke, Parkinson's disease (PD), and dementia. This includes helping people work through anxiety, depression, trauma, grief and loss, stress, adjustment to health changes, management of symptoms, and relationship challenges. In addition, she has expertise in navigating healthcare systems and facilitating community linkages. Jennifer has assisted in developing and implementing the Healthcare Navigator (HCN) service at Parkinson Society BC (PSBC).

### **Tell us about the new Healthcare Navigator service offered at Parkinson Society BC. How does it connect people touched by Parkinson's disease with healthcare resources and social services in British Columbia?**

Parkinson Society BC's Healthcare Navigator service was established in April 2022 in response to a service gap identified whereby many people with Parkinson's disease and their carepartners required additional practical assistance accessing healthcare systems and resources. The Healthcare Navigator role recognizes that the job of accessing, understanding, evaluating, and applying knowledge from health systems is a daunting task, which falls

primarily on those affected by PD, many of whom are vulnerable older adults. Carepartners/caregivers also often take on the responsibility of understanding and accessing health services, while also juggling other responsibilities like providing care, managing households, and working.

The HCN aims to help people understand how systems work, recognize key players and points of entry, learn strategies to communicate, document and advocate when maneuvering within systems, and identify solutions to resource limitations. The goal of the Healthcare Navigator service is to reduce the social and economic inequities that result from the inability to adequately access resources. By helping connect people to appropriate services and supports, the HCN hopes to increase understanding, self-management skills, and self-reliance, as well as enhance the quality of life for both the person with PD and their carepartner/caregiver.

### **What types of services and resources can the Healthcare Navigator help with?**

The HCN employs a client-centered approach to assist people living with PD and their carepartners in accessing healthcare and social services systems. The HCN process usually involves several different steps, such as establishing contact, assessment, planning, implementation, follow-up, and wrap-up. The types of services and resources the HCN can help with include:

- Access to home and community care offices within the Health Authority, including home care, respite care, equipment, occupational therapy, case management, and facility care
- Private home support services, resources, and residential care in their community
- Future care planning resources, such as independent living, Representation Agreements, healthcare directives, facility placement, and hospital systems
- Financial resources, such as the disability tax credit and disability benefits
- Assistance accessing community services and resources, such as meal programs and transportation

**What are some of the most common obstacles that people with Parkinson's face when trying to access resources in their communities?**

There are numerous barriers to accessing healthcare resources. It is very difficult to grasp how systems operate, to understand the technologies utilized, and to find the exact entry point and make your way efficiently through multiple complex systems (for example, home/community care and long-term care). One system may be different from another and the learning curve for each can be steep. It can be a challenging, frustrating, time-consuming, and exhausting process for those impacted by PD, especially as they are often managing several chronic health conditions, multiple roles, and additional responsibilities. Additional obstacles may be experienced by those experiencing cognitive difficulties, financial challenges, limited support systems, and geographic isolation.

**What advice do you have for individuals navigating the often-complex healthcare system in this province?**

First, it is important to think about the big picture. Healthcare systems are large entities and navigating them is a complex undertaking. Most large complex systems have many moving parts and different people working within them, each with their own set of roles and responsibilities. Systems are structures that have a function with rules and processes that usually need to be followed, which may change over time. For example, hospitals are big systems whose function is to treat injured or ill people. They have different departments (such as medical imaging or the emergency room) and many different people, such as nurses, ultrasound technicians, and orderlies, all performing specific tasks using a vast array of equipment and technologies. It's hard to change entire systems, but you can try to understand how they work, to make them work better for you.

Then, think about the smaller picture. Healthcare Navigation involves a broad set of skills and knowledge, which can be learned and used to access services. It is an essential part of self-advocacy and empowerment.

Knowledge is power. Focus on building key skills, like planning, organization, and strong communication to be the most effective service navigator and to get the best care for yourself or your loved one. Don't do this all on your own. Reach out to friends or family. If you are feeling overwhelmed, ask for help from professionals.

**We talk a lot about the importance of self-advocacy in our programs and resources. How can people with Parkinson's better advocate for themselves when accessing healthcare?**

The Healthcare Navigator helps people acquire systems knowledge and teaches them skills and strategies to maneuver within health and social systems, so that they can better advocate for safe and adequate care for themselves and their loved ones. These skills and abilities can be used throughout a lifetime.

A practical thing I recommend is keeping a health notebook (for yourself and your family member) to record information, symptoms, and questions. This assists you in being proactive and informed about your own health and well-being. Also, I advocate the "oxygen mask on yourself first" analogy. To care well for others, we must care for ourselves. It is so hard to do, but so important.

**How does accessing resources differ for those living in more rural communities? What advice do you have for them?**

For people who live in more rural and remote communities, there may be many added challenges in accessing health services due to geographical isolation, limited availability of resources and access to services, transportation difficulties, and harsh weather conditions (for example, snow and ice). Accessing resources online, finding creative "out of the box" solutions, connecting virtually using social media, and sharing information with others who also live in rural settings can be helpful for those in remote communities.

**How can individuals contact you for assistance?**

Referrals to the Healthcare Navigator can be made through Parkinson Society BC's Information & Referral Program. If you think that you can benefit from this service, please reach out to us at 604-662-3240, 1-800-668-3330, or [info@parkinson.bc.ca](mailto:info@parkinson.bc.ca).

# Research

## Influence of fatigue in Parkinson's disease on gait performance and locomotor control mechanism

Dr. Caroline Paquette is conducting a study to investigate how fatigue affects how people with Parkinson's disease (PD) walk and move. Fatigue is a common issue for people with PD. It impacts their everyday life and tasks, making them harder to perform and reducing their quality of life. Fatigue isn't just about being physically tired; it can also involve feelings of mental and emotional exhaustion, all of which could be connected to changes in the brain linked with PD.

The aim of the pilot study is to explore whether changes in brain activity, related to fatigue, occur when people with PD walk. Moreover, the study will examine how fatigue influences the control of movement and overall walking ability in PD patients. To do this, the study will involve 24 participants. They will be divided into two groups: one group who are experiencing fatigue and one group who are not. Each participant will be asked to complete a set of questionnaires covering different topics, such as their feelings of fatigue, mood, sleep quality, physical symptoms related to PD, and their level of physical activity.

In addition, participants will be asked to wear an activity tracker, similar to a fitness watch, for five days. This will measure their physical activity levels. They will also keep a daily diary, recording their activities, sleep quality, mood, levels of fatigue, and anything that seems to make their fatigue worse.

Next, participants will undergo two brain scans. These scans will measure the activity in different areas of the brain while they walk, with special attention to areas that might be linked with feelings of fatigue. The researchers will use special motion sensors to carefully assess any effects of fatigue on the participants' ability to walk, especially during more complex tasks.

Lastly, a series of interviews will be conducted to explore more deeply the experiences of fatigue. By understanding the many ways fatigue can be experienced, researchers hope to gain a better understanding of this symptom.

This study is crucial because there is much we still do not understand about fatigue in PD. Fatigue can greatly impact a person's ability to walk and perform daily activities, so it is important to understand its relationship with movement and the associated brain mechanisms. This pilot study is taking an innovative approach to unravel the complex experience of fatigue in PD, from the multidimensional symptoms to its relationship with brain activity during complex tasks like walking.

*The insights gained could pave the way for new strategies to manage fatigue and improve quality of life for people with PD.*

### RESEARCHER

Dr. Caroline Paquette

### INSTITUTE

McGill University

### PROJECT GRANT

\$75,000 over one year, funded by Parkinson Society British Columbia through the Parkinson Canada Research Program

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# Living Well

## Should people with Parkinson's delay starting medication?

The question of when to start medication is one most people with Parkinson's disease (PD) will need to consider at some point in the course of their illness. As PD is caused by a degeneration of the cells that produce dopamine in the brain, medications, commonly in the form of levodopa or dopamine agonists, aim to restore a balance of this important neurotransmitter in order to alleviate troublesome symptoms. Despite their efficacy, many people with Parkinson's may be hesitant to start taking medications. They may worry about bothersome side effects, potential long-term toxicity, and whether or not the medications speed up disease progression or lose effectiveness over time.

Worrying about side effects is the top reason people with Parkinson's are hesitant to start medication (*Mestre et al., 2014*). Their fears are not completely unfounded – younger individuals with Parkinson's are particularly at risk of developing levodopa-induced dyskinesia, a common side effect that is characterized by abnormal, involuntary movements. This is why another class of drugs called dopamine agonists may be the best choice at the beginning of their treatment. While these drugs may provide symptom relief for a long duration of time in those who can tolerate them, dopamine agonists are not ideal for everyone. For a small subset of individuals, they have been associated with the emergence of behavioral changes, such as impulse control disorders (*Thanvi et al., 2007*).

One unique study looked at motor side effects, such as dyskinesias, as a result of levodopa use. Individuals with Parkinson's disease from Italy and Ghana were compared. Those from Ghana had experienced symptoms of PD longer before starting levodopa, as economic factors resulted in limited access to medication. When compared to people from Italy, who commenced medications much sooner after the onset of symptoms, both groups developed motor complications, like dyskinesia, from levodopa at similar stages of disease progression. Thus, it appears that how long someone has had Parkinson's disease, not the timing of starting levodopa, is responsible for the emergence of motor complications. In fact, several studies have shown that motor side effects and dyskinesias first appear approximately six to seven years after symptoms begin, regardless of when levodopa was started. The authors therefore concluded that there was no benefit in delaying levodopa (*Cilia et al., 2014*).

Despite the risks of dyskinesia, behavioural changes, and other unwanted side effects, there are risks to delaying medication. Uncontrolled motor



symptoms of Parkinson's disease can increase the likelihood of falls, which can lead to fractures, hospitalization, and other adverse health outcomes. While it is completely reasonable to consider the pros and cons of taking medication, it is important to keep in mind that choosing to delay medication comes with its own set of risks and rewards.

Beyond the concerns of side effects, many people with Parkinson's, as well as researchers, have wondered about levodopa's long-term safety and whether it is toxic for humans. Some in vitro studies (conducted on cells in laboratories, often grown in petri dishes) have shown that levodopa can possibly degenerate dopamine neurons, but similar findings in humans or animals have not been found (*Mytilineou et al., 2003*). One reason why levodopa may be toxic to cells in a petri dish, but not to cells within a human brain, is because neurons in the brain are supported by a network of glial cells, which protect and transport nutrients to them. There are far fewer glial cells in in vitro conditions, making those neurons more vulnerable. One researcher notes that in addition to levodopa, oxygen and calcium are also more toxic in vitro (*Agid, 1998*).

A randomized, double-blind, placebo-controlled study (the gold standard of scientific research) on 361 people with Parkinson's disease sought to uncover whether levodopa use could accelerate neurodegeneration. Study participants were split into two groups – one receiving levodopa, another receiving a placebo – for 40 weeks. They were not allowed to take any other anti-parkinsonian medication during the study. At the end of the study, participants underwent a two-week “washout” period, which meant they stopped taking the medication to clear it from their system, giving the researchers an ability to see if the medication made a clinical difference in their disease progression. They found no evidence that levodopa made Parkinson's any worse. In fact, when compared to the group receiving a placebo, the participants in this study taking levodopa actually had less worsening of their PD symptoms, which could possibly suggest levodopa may slow disease progression. However, the researchers cautioned that future research

is needed on this topic to conclusively determine if levodopa is protective, harmful, or neither (*The Parkinson Study Group, 2004*). Another study compared starting levodopa early versus late and found no significant differences in outcome between the groups at the end of the study period (*The LEAP Study Group, 2019*).

Additionally, some people consider delaying medications in fear that they will lose their efficacy over time. Fortunately, this does not seem to be the case either. As the disease progresses, people with PD will need to take more medication, not because the drugs are losing their effectiveness, but rather because there are less dopaminergic neurons in the brain, and therefore a worsening of symptoms occurs. There also may be misunderstandings about what drugs like levodopa can help with. Non-motor symptoms, such as depression, cognitive problems, and bowel/bladder issues cannot be treated with levodopa and may develop as PD advances. The inability of levodopa to treat these symptoms may lead someone to incorrectly think that it is losing its effectiveness (*American Parkinson Disease Association, n.d.*).

**Exercise has, time and time again, been shown to be one of the most powerful non-pharmacological treatments available for PD.**

If, for whatever reason, you choose to delay medication, know that there are alternative options you can try. Exercise has, time and time again, been shown to be one of the most powerful non-pharmacological treatments available for PD. Exercises that incorporate movement, balance, flexibility, and coordination, such as tai chi and yoga, can be especially helpful for motor symptoms. Movement therapies, like the Alexander Technique, may also be beneficial for mobility in people with PD (*Hopkins Medicine, n.d.*).

If you have any questions about medication, make sure to speak with your doctor or pharmacist.



#### ADDITIONAL RESOURCES

- **PD Medication: What You Need to Know**  
Helpsheet: <http://bit.ly/parkinsonsmedication>
- **Ask the Expert: Parkinson's Medication Q&A with Amy Tran, Pharmacist**  
YouTube Video: <https://bit.ly/pdmeds-pharmacist>

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# Carepartner's Corner

## Cognitive Behavioural Therapy for carepartners

Caring for someone living with Parkinson's disease (PD) can be both rewarding and demanding, resulting in the carepartner experiencing a range of emotions throughout their journey. While every emotion is valid, carepartners may find that certain ones, like loneliness, anxiety, and sadness, contribute to burnout and depression. Fortunately, there exists a well-studied, evidence-based psychological treatment called Cognitive Behavioural Therapy (CBT) that can help carepartners reframe their thoughts (also called cognitions), which, in turn, will have a positive impact on their emotions and behaviours. The result is that carepartners can lead more fulfilling, happy lives. One study of 30 caregivers of people with Parkinson's showed that three months of CBT resulted in caregivers reporting less strain and emotional burden. The especially promising finding was that the benefits appeared to persist long after the initial CBT treatment (Secker & Brown, 2005).

At the heart of Cognitive Behavioural Therapy lies the idea that our thoughts, emotions, and behaviours are interconnected. CBT places a strong emphasis on the importance of changing irrational thinking patterns, as they can lead to unhealthy emotions and behaviours. Changing unhealthy patterns also often results in someone feeling better and adopting a more balanced view of themselves and the world. However, it is important to clarify that CBT is not about forcing yourself to think only positive thoughts while ignoring negative feelings.

To demonstrate the link between thoughts, emotions, and behaviours, an example scenario is useful. Let us say a friend calls you and offers

to care for your loved one for a few hours so you can have some respite. Using the examples below will help to illustrate the three types of cognitions in the CBT model:

- 1. Automatic negative thoughts (ANTs):** these thoughts occur without our conscious awareness, usually immediately in response to an event. ANTs make up a large portion of self-talk. Because they are often fleeting in nature, it is common to notice the emotions they invoke, not the thoughts themselves. This is why sometimes we feel a negative emotion, but cannot pinpoint the precise thought that led to the feeling. One of the most powerful ways CBT helps us feel better is by breaking a situation down slowly and uncovering the negative thoughts that spark our emotions.

*In the scenario above, your automatic negative thought might be, "I shouldn't accept help from my friend. They are probably too busy with their own life, anyway. I should always be able to provide care without anyone's assistance."*

- 2. Cognitive distortions:** these are irrational, unhealthy thinking patterns that reinforce automatic negative thoughts. Because humans have a tendency to focus on the negative more easily than the positive, our perceptions of reality can easily become distorted. A few types of cognitive distortions include: **overgeneralization** (seeing a pattern based on a single event), **catastrophizing** (seeing only the worst possible outcome), **all-or-nothing thinking** (using absolutes, such as "always" and "never"), **mental filtering** (only acknowledging information that fits a negative belief system), and **jumping to conclusions** (imagining you know what others are thinking, as well as predicting something bad will happen without evidence).

*In the scenario above, the cognitive distortions experienced may be all-or-nothing thinking and jumping to conclusions.*

**3. Core beliefs:** these are thoughts we have adopted as truth about ourselves, others, and the world. Core beliefs are often informed by early experiences, as they were a way we made sense of the world in childhood. They become the lens through which we see everything, but it is important to note that no matter how compelling or true they feel, they are merely beliefs.

*In the scenario above, a core belief might be, "If I am not perfect, I am not good enough." Another might be, "People are unreliable, and I cannot depend on them."*

Using the example above, the negative thoughts may lead to feelings of sadness or even irrational anger at your friend for offering their help. As a result, your behaviour might cause you to isolate yourself. If you feel sad and isolated, you are more likely to continue to have negative thoughts – and so the cycle continues.

**CBT proposes several interventions that can help you reframe your negative thoughts so you feel better and behave in healthier ways. They include:**

- **The ABC model:** this model helps you understand your irrational and negative beliefs by breaking a situation down into the **A activating** event (what happened), your **B beliefs** (the meanings you assign to the event), and the **C consequences** (the emotions and behaviours you experience). We often think that an activating event directly leads to consequences (ex: "My husband's behaviour made me so angry!"), but frequently fail to recognize that the meaning we place on the event plays a big role in how we feel and subsequently act. By exploring and challenging negative beliefs, you can actively change how you respond to a situation.
- **Cognitive restructuring:** this tool can help you identify and reframe irrational beliefs. One way to do this is through decatastrophizing, which can help you examine different outcomes of an event, including the worst-case scenario. By breaking down a frightening or unpleasant event

and considering the worst case, we often find we are more prepared and capable of handling the situation than we originally expected. Another form of cognitive restructuring is to challenge negative thoughts by asking questions like: "Is there another way to look at this situation?", "Am I making assumptions?", "What would I tell a friend in a similar situation?", and "Is there any evidence to support this worry?"

- **Behavioural experiments:** this technique involves identifying any expectations and worries you have about a situation, predicting the outcome you think will occur, and then testing your hypothesis. Many times, you will be surprised that the negative outcomes predicted do not happen or are less severe if they do.

While there are ample self-help resources for Cognitive Behavioural Therapy, you do not have to do it alone. Parkinson Society BC offers free short-term, non-crisis counselling services for people touched by Parkinson's disease. Counselling can provide you with a safe and structured environment to discuss and process emotions, learn new coping strategies (including CBT), and provide you with the extra support you and your loved one(s) may need. To learn more, visit [www.parkinson.bc.ca/counselling](http://www.parkinson.bc.ca/counselling).

#### ADDITIONAL RESOURCES

- **Asking for and Accepting Your Own Support**  
Website: <https://bit.ly/askingacceptingsupportpd>

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**VIOLA CHAN**  
PERSON WITH PARKINSON'S

Viola will be featured in a segment with Fairchild TV on April 22, 2023 to discuss her journey with Parkinson's disease. Further details will be provided on Parkinson Society BC's website once the interview is available.



## Our Mission

Empower people with Parkinson's in British Columbia through providing resources and services to enable self-management, self-reliance, and self-advocacy.

## What is Parkinson's Disease?

Parkinson's disease is caused by a loss of dopamine in the brain and is the second most common chronic neurodegenerative disorder after Alzheimer's disease. Both motor and non-motor symptoms may be experienced, such as tremor, rigidity, slowness of movement, difficulty with speech, sleep disturbance, and mood disorders.

*There is currently no known cure.* It is estimated that there are approximately 15,000 individuals living with Parkinson's in British Columbia. Experts predict that the incidence of Parkinson's will double by 2040. While the vast majority of people with Parkinson's are over 60, 20% are diagnosed before the age of 50 and many are in their 30s and 40s.

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- Stan and Tilly Wiebe
- Sean Wiens
- Paul and Marguerite Zakus
- Sherri and Julian Zelazny

## INDIVIDUALS

### Tulip Circle - \$500-\$999

- Anonymous (54)
- Janie Ackhurst
- Rob Aird
- Raymond and Doreen Alleyne
- Clifford and Carol Anderson
- Frank Anfield
- Craig Barton
- Lisa Beck
- Georgina and Barry Beddome
- Brian Begert
- John Benmore
- Barbara Bilstrand
- Jill Boileau
- Sheryl Bolton
- Evelyn Bowersock
- Judy Brown
- Sylvia and Peter Bull
- Mark and Susan Bullock
- Stephen Carlman
- Viola Chan
- Melissa Cheevers
- Felicia Chen
- Harmandeep Singh Chhina
- David and Debbie Couling
- Nancy Coutts
- Pamela J. Cowan
- Barbara Cox and William Reed
- Paul Crofts
- Diane and Hubert Daignault
- Tony Dawson
- Barb and Gary Dean
- Elzo and Lynn deVries

- Prabhjot Dhillon
- Gavin Dirom
- Bruce and Delight Dobby
- Sheila Dodgshon
- Scott and Judy Drever
- Sharon Dyball
- Lorraine Fedorak
- Edward Fenn
- Nigel and Joan Fitzpatrick
- Stella Floro
- Alfred Forbrich
- Louise and Richard Fortin
- Kimberley Francis
- Sandra L. Fritz
- Alistair Galbraith
- Beverly and Kenneth Gelhorn
- Doug and Shannon Grant
- Steve and Lynda Grisack
- Marjorie Groves
- Annette Guenard
- Sandra Harrison
- Katharine Hennebery
- Kerry Hiebert
- James Higgins
- Holland Family Foundation
- Paul Hollands
- Victor Hori and Heather M. Yamada
- Sean Irvine
- Marnie Jarvis
- Peter M. Jarvis
- Penny Jennings
- Donald Kassa
- Jeff and Wendy Keeble
- George and Helen Kerr
- Sam Kerton
- Gerald and Debbie Koroll
- Pluto and Venus Kwon
- Mike Larsen
- Beverley Stanich's Family
- Murray Leith
- Marian Lewis-Peel
- Barbara Lockyer
- Colin and Kate MacBeath
- Doug MacDonald
- Michael MacKie
- Ronald MacRae
- Leanne and Craig Mah
- Tyrell Mara
- Patricia Mauch
- Barry and Barbara McBride
- Shirley McGillivray
- Bruce A. McIntyre
- Joanne Mcleod
- Max and Margrit Meier
- Ben and Dorothea Meulenbeld
- Roger and Dominique Miller
- Dr. Peter J. Molloy
- Brenda Mounce
- Mary Mowbray
- Harry and Elsa Murphy
- Margaret E. Mutch
- Todd Nicklin
- Mavis and Walter Norman
- Nick Nuraney
- Chris O'Connor
- Fumiko Oguchi-Chen
- Elizabeth Ohlson
- Gordon and Wendy Olinger
- Bob Oliver
- Kenneth Orchard
- David Pearson
- Iris Pierrot
- Dawn and Alan Pollock

- David Probst
- Leighton F. Pullen
- Dr. Allan Quigley
- Blair T. Quinn
- Deborah and Dave Ralston
- Mary Ann Elizabeth Ray
- Dr. Karla Reimer
- Eve and Jim Rimell
- Jenny Rinsma
- Marc and Vicky Rizzardo
- James Rogers
- Pam Rosengren
- Manvinder Sahota
- Greg and Danielle Schroeder
- Andrew Scott and Katherine Johnston
- Maritta E. Seiler
- Toni and Jon Shapiro
- Bill and Carol Skjaveland
- Bill and Myrt Smeaton
- Ian Smith
- Robert M. Smith
- Arthur Smolensky
- Alicia Soon
- Ian Speckman
- Iris and Gordon Spencer
- Kareen Stanich
- Julie Steiner
- Lorraine and Allen Sundval
- Barry Taylor
- Mike and Cindy Trotman
- John and Linda Trueman
- Thomas Tully
- Patricia J. Twohig
- Jasdeep Uppal
- Tracey and Anibal Valente
- Monica and Gary Vaughn
- Judy Vogt
- Connor Waddell
- June Wakefield
- Kathleen and Terry Wallden
- Val Walters
- Maire and Duncan Watson
- Bryan White and Glennis Davidson-White
- Max Whitney
- Jeffrey S. Wicharuk
- James Wiggins and Duane Cromwell
- Jodi Wijenberg
- Monique Wilberg
- Carol L. Williams
- Taylor Williams
- Toni Williamson

## ORGANIZATION

### Leadership Circle - \$5,000+

- A&W (Newton/Strawberry Hill/ Cloverdale, Surrey/Glenlyon, and Burnaby)
- AbbVie Corporation
- Aqueeduct Foundation
- Bank of Montreal
- Bell Media
- BMC Networks Inc. Technology Services
- Corus Entertainment
- The Eagle Family Fund, held at Nicola Wealth Private Giving Foundation
- The Lewis Family Fund, held at Nicola Wealth Private Giving Foundation
- Frances A. McClean and Charles J. McNeely, Jr. IMP Fund, held at Vancouver Foundation

- Ocean Park Foundation
- Provincial Employees Community Services Fund
- Stingray Radio
- The Raven Foundation
- The River Foundation
- The Alan and Doreen Thompson Charitable Foundation

## ORGANIZATION

### Benefactors Circle - \$1,000+

- Antham Capital Corp
- Bond Repro
- Canada Life
- Coast Capital Savings
- District of Sparwood
- Fidelity Investments Canada ULC
- Gorman Bros. Lumber Ltd.
- Grant from Audre Jackson for the Sarah Jackson Memorial Fund via Gift Funds Canada
- HAB Family Foundation
- IMPACT Parkinson's
- Jakobsen Foundation via Strategic Charitable Giving Foundation
- JD Gatz Media Inc
- Kamloops Parkinson Awareness Group
- King Bin Inc.
- Little Mountain Landscaping Ltd
- Loyal Order of Moose Lodge #1552
- McElhanney Ltd.
- Mega Electric Ltd
- Me-n-Ed's Enterprises Canada Ltd.
- Omineca Fabricating
- RBC Foundation
- RBC Royal Bank (Sparwood)
- Royal Bank Financial Group Foundation
- Royal Canadian Legion Branch No. 52
- Shawn G. Foundation, held at Vancouver Foundation
- Sparwood Hose & Fittings
- Sunovion Pharmaceuticals Canada Inc.
- Teck Coal Limited
- TELUS
- The Fograscher Family Fund, held at Nicola Wealth Private Giving Foundation
- The Hamber Foundation
- The Pekarsky Family Foundation
- Waypoint Insurance
- Whites Location Equipment Supply Inc.
- Wilson M. Beck Insurance Services Inc.

## LEGACY GIFTS

- Estate of Marilyn Jean Angus
- Estate of Laurence Hayden Chisholm
- Estate of Anne Maureen Robertson
- Estate of Bryan James Sask
- Estate of Frank Alfred Storey
- Estate of Thomas John Kenneth Thompson
- Estate of George Kennedy Tough

**Note:** We strive to ensure that each name is appropriately listed and spelled. Please let us know if we have made an error so we may correctly recognize you in the future.

# Executive Message

In 2022, we at Parkinson Society British Columbia have worked tirelessly to further our mission of empowering the Parkinson's community in this province. Throughout the year, we continued to inform our decisions by building and maintaining connections with the individuals that rely on us, including carepartners, families, people with Parkinson's disease, and healthcare professionals. Thanks to your generous support, here are some ways we are working to help people touched by Parkinson's disease in BC:

- The BC Ministry of Health confirmed funding for a second neurosurgeon to perform Deep Brain Stimulation (DBS) surgery in British Columbia. This step is essential in reducing the lengthy waitlist and improving the quality of life for those living with Parkinson's disease.
- We continue to invest in an innovative approach to expand holistic care for those affected by Parkinson's disease. We are providing incentive funding in two health authorities to support a team approach to care in the Victoria and Kelowna movement disorder clinics. We began a similar investment with Vancouver Coastal Health Authority for the UBC Movement Disorder Clinic, adding a part-time occupational therapist and part-time speech-language pathologist. We are investing \$500,000 over five years (2020-2024; 2021-2026) to improve care in each of these health regions. Funding was also offered to Vancouver Island Health Authority for a full-time speech-language pathologist in Nanaimo.
- We have increased access to specialized therapies by expanding our Virtual Physiotherapy service, which aims to reduce barriers to Parkinson's-specific treatments. For people meeting certain criteria, this service is available free of charge.
- We continue to provide free clinical counselling to both people with Parkinson's and their loved ones.
- To help individuals better navigate the complexities of the healthcare system, the Society has hired a new part-time Healthcare Navigator, an important addition in strengthening our information and referrals service.
- Our educational events continued to be provided in a primarily virtual format to remain as accessible as possible. However, we have also hosted several in-person events throughout the 2022 year, including our highly-anticipated provincial conference, Moving Forward, Together, which fostered an educational and inspirational space to enrich connections between people with Parkinson's, carepartners, friends, and healthcare professionals.
- We are continuing to invest in research through funding partnerships with Parkinson Canada and the Michael Smith Foundation for Health Research. These groups aim to build capacity among the next generation of Canadian researchers, contribute to the collective understanding of this complex disease, and further the search for a cure.
- We are ensuring that every person touched by Parkinson's has a community behind them by strengthening our provincial network of over 50 support groups, so that no one has to walk alone on this journey.

Thank you for helping us continue to support and uplift the Parkinson's community in British Columbia. Together, we can ensure that every person touched by this disease has the resources and services they need to live life to the fullest.

Signed,



*Jean Blake*  
Jean Blake CEO



*Andrew Davenport*  
Andrew Davenport CHAIR

# Message from Finance Committee

Our Picture of Financial Accountability  
To view a copy of our audited 2022 Financial Statements, please visit [www.parkinson.bc.ca](http://www.parkinson.bc.ca).

## Revenue 2022

Donations	\$656,943
Special Events	\$470,560
Bequests	\$232,169
Investments + Other Income	-\$442,931 Net Unrealized Loss

## Expenses 2022

Support Services: \$1,254,195	58%
Research: \$427,500	20%
Fundraising: \$315,938	15%
Public Awareness, Communication & Advocacy: \$95,132	4%
Governance & Administration: \$77,807	3%

The Society enters 2023 with reserves equal to 18 months of its historical expenses, which provides the Board with further opportunity to actualize our strategic priorities. The Board continues to review opportunities to further increase the Society's impact and reach throughout BC.

# Our Year in Review 2022

## THANK YOU TO OUR VOLUNTEERS

**3,122+**

Hours Provided to Support the Society's Programs, Services, Advocacy, and Fundraising



Volunteers at Parkinson SuperWalk in Vancouver 2022

## FUNDRAISING

**\$384,832**

Raised for Superwalk

**PARKINSON  
SUPERWALK®**

## LEGACY GIFTS

**\$232,169**

Given from the Estates of Seven Individuals

## PD Connect®

**109**

Referrals from Healthcare Professionals through our PD Connect® Program



*Moving Forward, Together*  
provincial conference in 2022



**297**

Attendees at our Provincial Conference, *Moving Forward, Together*

## CONSULTATION + INQUIRIES

**1,773**

Information and Referral Inquiries

**68**

In-Depth Consultations

## COUNSELLING

**1,001**

Hours

**183**

New Clients



Parkinson SuperWalk in Abbotsford 2022



PD Warrior certification training in Kelowna, September 2022

## Other Achievements

Held two PD Warrior Training Courses for 58 Healthcare Professionals.

Hosted virtual open houses for the community that provide an overview of the programs and services offered by the Society

Supporting those with that have limited access to, or knowledge of, technology by offering printed resources by mail.

Introduced a Deep Brain Stimulation (DBS) Support Group for those who have received DBS surgery.

Provided professional facilitator training to our support group facilitators.

Launched a new healthcare navigation service designed to help the Parkinson's community better navigate the complexities of the healthcare system.



PD Warrior certification training in Vancouver, September 2022



(Left to Right) Jaqueline Hubick, support group facilitator, Liz Janze, Education and Support Services Coordinator at PSBC, & Jean Blake, CEO of PSBC at Facilitators' Training in 2022

### PHYSIOTHERAPY

248

Virtual Hours

37

New Clients

### WEBINARS

173

Exercise, Activity, and Education Webinars

4,635

Participants Served

## Board of Directors

### EXECUTIVE COMMITTEE DIRECTORS

**CHAIR**  
Andrew Davenport

Michelle O'Connor,  
John Hougan,  
Mark Hutchinson,  
Sean Lee, Jim Wu,  
Richard Mayede,  
James Patterson,  
Cec Primeau,  
Elisabeth Sadowski,

**VICE CHAIR**  
Dave Rickards

**SECRETARY**  
Sherri Zelazny

**TREASURER**  
Martie Rose Mendoza

**MEDICAL ADVISOR**  
Martin McKeown

## Our Staff

**CHIEF EXECUTIVE OFFICER**  
Jean Blake

**COUNSELLORS**  
Tricia Wallace,  
Madelaine Ross,  
Courtney Doherty

**DONOR & MEMBER SERVICES COORDINATOR / OFFICE MANAGER**  
Susan Atkinson

**SENIOR MANAGER, RESOURCE DEVELOPMENT & COMMUNICATIONS**  
Alicia Wrobel

**EDUCATION & SUPPORT SERVICES COORDINATORS**  
Alana Dhillon,  
Liz Janze

**SPECIAL EVENTS & FUNDRAISING OFFICER**  
Caroline Wiggins

**EDUCATION & SUPPORT SERVICES COORDINATOR / PHYSIOTHERAPIST**  
Shelly Yu

**MARKETING & COMMUNICATIONS, SENIOR COORDINATOR**  
Mirela Prime

**HEALTHCARE NAVIGATOR**  
Jennifer Allen

**MARKETING & COMMUNICATIONS COORDINATORS**  
Kat Perez, Nadia Ali



Vancouver 2022

# PARKINSON SUPERWALK®

## Save the Date!

Parkinson SuperWalk will return to British Columbia the weekend of  
**September 9 & 10, 2023**

Registration and information available beginning May 8th at:

[parkinson.bc.ca/superwalk](https://parkinson.bc.ca/superwalk)



**Parkinson Society  
British Columbia**

**Charitable Registration Number:**  
11880 1240 RR0001

**Phone:** 604-662-3240  
**Toll Free:** 1-800-668-3330  
**Fax:** 604-687-1327

**Address:**  
Suite 600-890 West Pender St,  
Vancouver, BC V6C 1J9

[www.parkinson.bc.ca](https://www.parkinson.bc.ca)  
[info@parkinson.bc.ca](mailto:info@parkinson.bc.ca)

**Follow Us:**  
@ParkinsonsBC

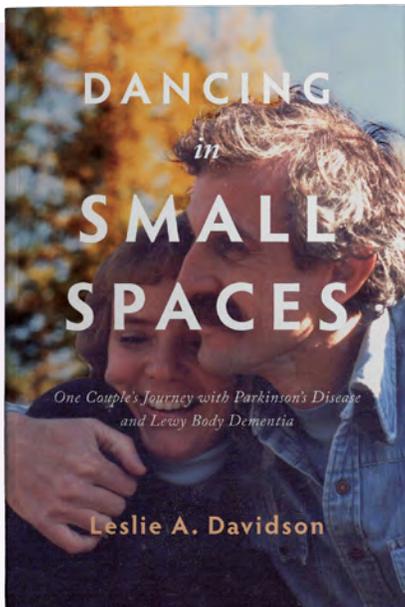


# Stories

## Dancing in Small Spaces

Leslie Davidson's book, *Dancing in Small Spaces: One Couple's Journey with Parkinson's Disease and Lewy Body Dementia*, is an unstintingly honest and surprisingly humorous memoir that charts a couple's parallel diagnoses of Parkinson's and Lewy body dementia. Just prior to its publication in late 2022, Leslie generously reached out to Parkinson Society BC with an offer of donating a book to each support group who wished to receive one; in the end, 21 groups expressed interest in receiving a copy.

Leslie is also the author of two children's books, *In the Red Canoe* (Orca Books, 2016) and *The Sun is a Shine* (2021). Her essay, "Adaptation", won the CBC Canada Writes Creative Non-fiction Prize. Leslie's work has been published in the *Globe and Mail*, *Viewpoints*, and *On the Move*. Leslie is a retired elementary school teacher, a mother, and grandmother. She lives in Revelstoke, BC.



To learn more, please visit

[leslieadavidson.com](http://leslieadavidson.com)

*An excerpt from Dancing in Small Spaces: One Couple's Journey with Parkinson's Disease and Lewy Body Dementia can be found below:*

One day, in the liquor store, I find myself juggling more bottles of wine than I can manage.

"Oh, oh," I say aloud.

A nice, youngish man comes to my rescue. He swoops in and tries to grab the bottle threatening to wobble its way out of my left hand. Instead of letting go of the bottle, I clutch it tightly and dramatically to my chest. The Parkinson's brain is a funny thing and often there is a disconnect between the intention and the message that miscreant neurons send to the rest of the body. It's called dystonia and it is not cool. Nice Man, dear heart that he must be, looks a little perplexed but hangs on, still determined to save both me and my wine, despite the fact that his hand, my hand, and the Ehrenfelser are slammed close to my left boob.

"I have a thing," I stammer. "Just give me a moment." And he does.

I try to speak politely to people, even when I am upset, and my wayward body parts deserve the same courtesy. After all, they really aren't in control. Nothing is in control. That's the nature of the beast.

*Hand, I silently plead. Big breath and then another. Hand, you can let go now.*

My hand relaxes. Nice Man saves the wine and we walk side by side to the till.

"Thank you," I say. "I have Parkinson's disease. It can be weird."

He smiles and returns to complete his shopping. I walk home, just a few short blocks, but long enough to give me time, time to decide to laugh or cry. It makes a much better story for Lincoln if I laugh.

# Newsworthy

## Upcoming Education & Exercise Events

*Thursdays, Jun 1, 8, 15, & 22*

### **Let's Get Loud & Clear**

🌐 **Online**

Join us for a 45-minute group therapy class aimed at addressing voice and speech changes associated with Parkinson's. The class will be centered around the use of breath to enhance voice projection, with the goal of enabling participants to communicate more effectively with their loved ones.

*Tuesdays, Jun 6, 13, 20, & 27*

### **Rhythm in Motion (Level 3)**

🌐 **Online**

Join personal trainer Janey Enmil for this fast paced, high intensity exercise class, which will focus on rhythmic movements to the beat of music. Warm up, mobility exercises, balance, strength, and stretching will be incorporated. We welcome everyone to come join for a daily dose of motivation and movement magic!

*Tuesdays, Jul 11, 18, 25, Aug 1, & 8*

### **LOUD CROWD Voice Class**

🌐 **Online**

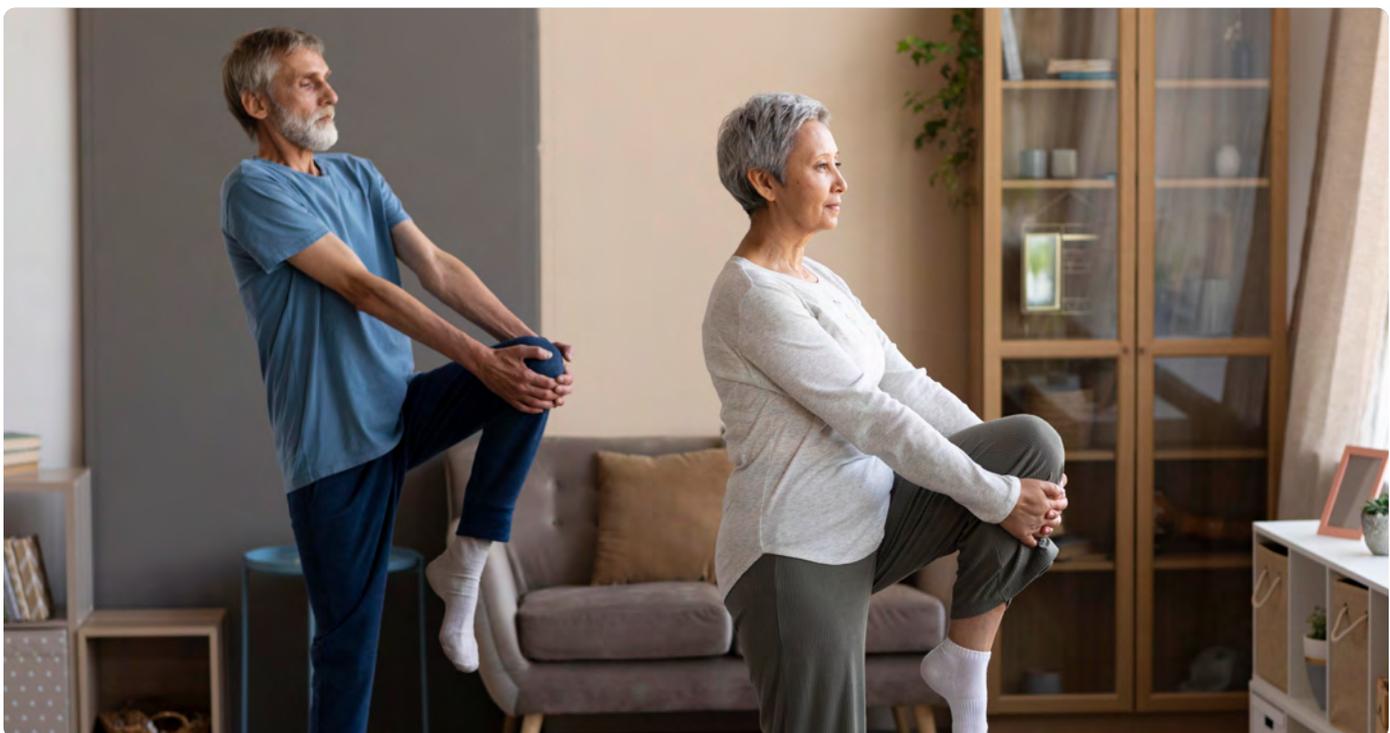
This voice class will be based on the Lee Silverman Voice Treatment (LSVT) LOUD® program principles and will help people with Parkinson's improve vocal loudness and communication ability.

*Thursdays, Jul 13, 20, & 27*

### **Seated Exercise Circuit (Level 2)**

🌐 **Online**

Join PSBC's own Neuro Physiotherapist, Shelly Yu, in a three-week series of seated exercises. This class is suitable for those who would like a moderately paced and high energy exercise class, yet all done while sitting. Classes will focus on various components of mobility, strength, and endurance to improve overall day-to-day function.



*Tuesdays, Aug 21, 28, Sep 4, 11, & 18*

## ***Popping for Parkinson's (Level 1)***

🌐 **Online**

Popping is a form of dance originating in California in the late 1970s, involving rhythmic contractions of the dancer's muscles to accent the beat. The key concept is to use the dance techniques as an innovative therapeutic tool for improving the physical condition of people affected by Parkinson's.

*Thursdays, Sep 7, 14, 21, & 28*

## ***September Challenger (Level 3)***

🌐 **Online**

Let's get moving! Kick-start the fall season with the September Challenger, a high-intensity and fast-paced exercise class suitable for those who can stand and move unassisted. PSBC's Neuro Physiotherapist, Shelly Yu, will challenge your balance, coordination, and exercise stamina in this fully standing circuit class.

*Saturday, Sep 16*

## ***Communication & Swallow, Victoria***

📍 **Location TBD**

Led by registered speech-language pathologist Jasmine Cload, this workshop will focus on addressing the communication and swallowing challenges experienced by people with Parkinson's. The workshop will be interactive and participatory, utilizing clinically proven methods from the Lee Silverman Voice Treatment® to enhance communication for participants.



## **Thank you to Our Fundraisers & Donors**

A big thank you to Me-n-Ed's Pizza Parlors for their fundraising efforts during the Sweetheart Pizza Sales on Valentine's Day! Through their dedication and hard work, \$462 was raised.

Thank you to the St. Francis Xavier School Parent-Teacher Association (PTA) for raising an incredible \$1,049 from their annual PTA Krispy Kreme Donut Sales!

📍 **Events Hosted in Person** 🌐 **Online Events**

## **New Parkinson's Biomarker Discovery**



Researchers have made a significant advancement in understanding Parkinson's disease by developing a new tool called  $\alpha$ -synuclein seeding amplification assay ( $\alpha$ Syn-SAA). This tool can detect the presence of abnormal alpha-synuclein, known as the "Parkinson's protein," in brain and body cells, not only in people with known Parkinson's, but also in those who have not been diagnosed yet. The  $\alpha$ Syn-SAA demonstrated remarkable accuracy, detecting abnormal alpha-synuclein in 93 percent of Parkinson's patients tested. The breakthrough offers hope for improved care and treatments, as well as the possibility of identifying individuals at high risk of developing the disease before symptoms start.

**Article adapted from:**

[www.michaeljfox.org/news/breaking-news-parkinsons-disease-biomarker-found](http://www.michaeljfox.org/news/breaking-news-parkinsons-disease-biomarker-found)

# PSBC YouTube

## Promo videos, tools, and educational resources

Parkinson Society BC (PSBC) offers a valuable resource for the Parkinson's community through our YouTube channel. This channel serves as a hub of information and support, featuring a library of videos that cover a wide range of relevant topics. Individuals living with Parkinson's disease, as well as their caregivers/ carepartners and healthcare professionals, can access insightful content on the latest research, treatment options, coping strategies, and lifestyle tips.

We have recently uploaded a variety of new content, including video recordings of our education and exercise events. Our educational webinars feature in-depth discussions on Parkinson's-related topics, providing viewers with expert perspectives. Additionally, we have uploaded recordings of our exercise events, ensuring that people with Parkinson's have the opportunity to participate in beneficial physical activity from the comfort of their homes.



To view our channel recordings, please visit [www.youtube.com/ParkinsonSocietyBC](https://www.youtube.com/ParkinsonSocietyBC)

### Uploads from PSBC



Larry Gifford's extraordinary Parkinson's Journey #MoreThanATremor



Brock Boeser on his dad's life with Parkinson's #MoreThanATremor



Move with Shelly - Standing Exercise (2022) Session 3/4



600-890 West Pender Street,  
Vancouver, BC V6C 1J9



RETURN POSTAGE GUARANTEED  
PORT DE RETOUR GARANTI