

# VIEWPOINTS



# Fall 2023

## VIEWPOINTS

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by Parkinson Society  
British Columbia

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## 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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# Ask an Expert

## Registered Speech-Language Pathologist Sherri Zelazny discusses common speech and swallowing problems in people with Parkinson's



**Sherri Zelazny** is a Registered Speech-Language Pathologist with more than 35 years of experience and clinical expertise in voice evaluation and treatment.

She has a long history of involvement with the Parkinson's community as a clinician providing Lee Silverman Voice Treatment® for Parkinson's for more than 20 years. She was the Vice President (now Honourary Member) of the Wisconsin Chapter of the American Parkinson Disease Association. She joined the Parkinson Society BC Board of Directors in November 2012. Sherri also contributed significant time and energy to piloting the Society's Communication and Swallow program in 2014 and continues to present this program. She is Past-President of Speech and Hearing BC (2017-2019).

### What are some of the common speech and communication problems in Parkinson's disease? What about swallowing problems? What impact do these issues have on daily living?

The most common communication difficulty that people with Parkinson's disease (PD) experience is low vocal volume or soft voice. Other communication changes can include hoarseness, mumbling, vocal tremor, and changes in speaking rate. Hypokinetic dysarthria is the diagnostic term used to identify communication problems typical of Parkinson's disease.

The most obvious signs of swallowing problems are coughing and choking; these issues can occur during or after eating or drinking. Other less obvious symptoms may include trouble swallowing pills, difficulty chewing, slower eating, avoidance of certain foods, drooling, fatigue with eating, difficulty starting the swallow, or recurrent lung infections. Dysphagia is the term used to describe swallowing disorders.

Changes in communication and swallowing often emerge before a formal diagnosis of Parkinson's disease. Early identification, evaluation, and treatment can help manage symptoms and maintain quality of life. We take our ability to communicate and eat for granted, including expressing our wants and needs, telling people we love them, and enjoying a meal with family and friends. Problems with communication and swallowing interfere with quality of life and daily wellbeing.

We know that more than 80% of people with PD will experience communication and/or swallowing challenges at varying levels of severity. A qualified Registered Speech-Language Pathologist (RSLP) can help evaluate, treat, and improve communication and swallowing safety to improve quality of life.

### What role does a Registered Speech-Language Pathologist have in treating communication and swallowing difficulties in people with Parkinson's?

Registered Speech-Language Pathologists provide behavioural evaluation and treatment for symptoms related to hypokinetic dysarthria and dysphagia. Treatment for communication and swallowing disorders for Parkinson's disease can be very effective. Patient participation is crucial, as it is in any therapy exercise program, as is early identification and treatment. For better outcomes, early contact with an RSLP is important.

### You are certified in Lee Silverman Voice Treatment® (LSVT®), one of the "gold standard" treatments for Parkinson's. What makes LSVT® so effective when compared to other therapies?

Scientifically validated over the last 30 years with research funding from the National Institutes of Health and other organizations, LSVT LOUD® is the only speech treatment with level one evidence, the highest level of evidence, for people with Parkinson's.

### Published outcomes on LSVT LOUD® have documented:

- Increased vocal loudness
- Improved articulation and speech intelligibility
- Improved intonation
- Improvements in facial expression
- Changes in neural functioning related to voice and speech

LSVT LOUD® is a standardized treatment protocol that is customized to the unique communication goals of each client. It can result in improvements in clients across a range of disease severities and communication impairments.

The dosage of LSVT LOUD® is consistent with principles of neuroplasticity including “Use it or Lose it and Use it and Improve it!” It is administered in an intensive manner to challenge the impaired system.

### What day-to-day activities can people with Parkinson’s do to strengthen their communication and swallowing abilities?

#### Some general tips for improved communication:

- Talk LOUDER!
- Look at the people you are talking to
- Talk in a quiet location
- Plan conversations for when you have more energy
- See a Registered Speech-Language Pathologist for voice exercises

After participating in therapy with a Registered Speech-Language Pathologist, there may be group voice activities appropriate for you that will help you continue practicing voice exercises, ensuring you maintain your progress.

#### Some general tips for swallowing safety:

- Focus on eating; do not talk or do something else at the same time
- Take small bits and sips, one at a time
- Chew your food well
- For each bite or sip you take, swallow two times
- Be careful using straws. The liquid can come in too fast making it difficult to swallow safely
- A spoonful of mashed bananas can help pills go down. Try one pill at a time
- If you notice coughing or throat clearing during or after eating, tell your doctor
- See a Registered Speech-Language Pathologist for swallowing exercises

Any activities that involve using your voice and swallowing muscles can help to keep the muscles active. Singing (on your own, karaoke, with a choir, or with a program such as SongShine) is great. Staying social, talking on the phone, talking with your family, and reading aloud are all activities that will keep those muscles moving.

The best exercise for swallowing is swallowing. Just like the general recommendation for physical exercise for people with Parkinson’s disease, talking, singing, and swallowing are all forms of exercise that can benefit your communication and swallowing abilities!

### What advice would you give someone who cannot, for whatever reason, access the services of a Registered Speech-Language Pathologist? Are there any self-guided treatments available?

This is a very difficult question to answer. In short, there are no self-guided treatments for communication and swallowing challenges in Parkinson’s disease. We would like everyone to have access to the services that mediate communication and swallowing problems in PD and improve quality of life. The best personalized care will be provided by a qualified Registered Speech-Language Pathologist after a comprehensive evaluation. Because British Columbia’s Medical Services Plan (MSP) does not cover outpatient rehabilitation outside of programs offered in hospital and at movement disorder clinics, it limits access to important services. Currently, services are available through movement disorder clinics across the province and private speech-language pathology providers. If you have extended benefits that cover “speech therapy,” you may be able to submit receipts from private service providers for reimbursement within the limits of your benefits. Swallowing evaluations and RSLP recommendations are always covered through MSP with a referral from a physician to your health authority.

Parkinson Society BC (PSBC) has been instrumental in improving access to services by funding speech pathologist positions in the Kelowna, Victoria, Nanaimo, and Vancouver movement disorder clinics. It is important that all people diagnosed with Parkinson’s disease have contact with the movement disorder clinic closest to them for the best access to available services.

PSBC's Communication and Swallow Workshops are also offered around British Columbia to help people better understand and identify hypokinetic dysarthria and dysphagia, explain importance of early evaluation and treatment, and introduce initial voice and swallowing exercises. The next Communication and Swallow Workshop is taking place on Saturday, September 16 at Lambrick Park Church in Victoria. Register today at [parkinson.bc.ca/csw-victoria23](http://parkinson.bc.ca/csw-victoria23).

### **Are there any assistive devices that can support communication and swallowing in people with Parkinson's disease?**

There are devices available, such as The Voice Aerobics Hi VOLT® Voice-on-Light Bracelet (which requires the user to wear the bracelet on their wrist; once their vocal volume reaches a sufficient level, the bracelet's light turns on, providing instant feedback) and SpeechVive (which utilizes an automatic brain response called the Lombard Effect, prompting louder speech as surrounding noise levels increase). These devices help individuals increase vocal volume. There are also various smartphone apps to help measure loudness and guide voice exercises, as well as reminding you to swallow. Additionally, there is respiratory muscle strength training that has shown effectiveness for communication and swallowing. Candidacy for benefitting from any of these devices should be determined after evaluation with a Registered Speech-Language Pathologist.

### **How do you assess and monitor the progression of communication and swallowing difficulties in Parkinson's disease? Does treatment change as the disease progresses?**

The Radboud Oral-Motor Inventory (downloadable at <https://bit.ly/radboudsinventory>) is a great way to self-monitor the status of communication and swallowing concerns and changes that may occur over time. Treatment is always customized to the unique communication and swallowing goals of each person. Early contact with a Registered Speech-Language Pathologist will help direct treatment over time based on disease progression in each person.

### **Are there surgical or medication treatments for speech and swallowing challenges for people with Parkinson's?**

So far, there are no surgical or medication treatments for communication and swallowing challenges. Having your medication regime optimized for your symptoms is best and will allow you to do all communication and swallowing exercises to the best of your ability. If communication or swallowing symptoms worsen with a medication change, be sure to tell your doctor as soon as possible.

### **How can healthcare providers help address the emotional and social aspects of communication and swallowing challenges?**

Early referral to a qualified Registered Speech-Language Pathologist is the most important step. If you have been diagnosed with Parkinson's disease, you are a candidate to benefit from services offered by a RSLP. Prompt attention to communication and swallowing challenges helps to maintain quality of life, including communicating with loved ones, working, enjoying meals with others, and socializing. From a much larger lens, we all need to advocate for access to publicly-provided allied healthcare services with the Ministry of Health for people with Parkinson's disease.

# Living Well

## When should you stop driving?



In British Columbia, the operation of motor vehicles is governed by the Motor Vehicle Act, which sets forth the regulations and guidelines for driving. RoadSafetyBC, a branch of the Ministry of Public Safety and Solicitor General, is responsible for ensuring road safety. RoadSafetyBC assesses drivers' medical fitness using the Driver's Medical Examination Report (DMER), which is required to be completed by someone's physician or nurse practitioner at age 80, 85, and every two years after. Assessments using the DMER were paused for two years due to the COVID-19 pandemic but have been resumed as of the spring of 2023 (*HealthLinkBC, n.d.*).

Drivers with known or suspected medical conditions, such as Parkinson's disease (PD), may be mailed the blue DMER form. The DMER serves as a crucial source of information for RoadSafetyBC's Driver Medical Fitness staff. It aids them in evaluating the severity, progression,

treatment, and effects of any medical conditions that a driver may have, which could potentially impact their ability to drive safely (*HealthLinkBC, n.d.*).

Section 230 of the Motor Vehicle Act also states that medical practitioners have an obligation to report patients to RoadSafetyBC if their medical condition poses a danger to their ability to drive, and if the patient disregards warnings and continues to drive. Depending on RoadSafetyBC's assessment, the Superintendent may impose conditions, request periodic reporting, or cancel the driver's license if necessary (*HealthLinkBC, 2021*).

While there is no set time for when someone should stop driving, there are several warning signs that indicate age or illness may be affecting our own or a loved one's driving safety. It is important to take these signs seriously, as individuals 70 and older are more likely to experience a crash than any other age group,

except those 25 and younger. Because of the natural physical vulnerabilities that come with older age, these drivers face a greater risk of severe injury or even death as a result of crashes. In fact, data collected by Transport Canada from 2000 to 2015 shows that 447 seniors died on average every year as a result of traffic accidents. These numbers include more than just drivers, however; pedestrians, cyclists, and other groups are counted as well. However, when only drivers are included, seniors make up the most driver fatalities of any age group (*CTV News, 2018*). What is also concerning is that most people continue to drive seven to 10 years longer than they ideally should, which puts them, as well as other road users, at risk (*HealthLinkBC, 2021*).

## How do you know when you should stop driving? The list below outlines some common warning signs (*HealthLinkBC, 2021*):

- 1. You have trouble following or remembering the rules of the road.** For example, you find yourself missing stop signs or red lights, or frequently have close calls with other road users. Other drivers may also honk at you for unintentionally dangerous actions.
  - 2. You struggle with the physical aspects of driving.** You may confuse the gas and brake pedals or find you cannot move your foot between them fast enough. You may also have difficulty turning your head far enough to shoulder check, or have trouble with your vision, especially at night or when there is a lot of glare. You may also notice your reaction time is not what it used to be.
  - 3. You have difficulty with road awareness and navigation.** You may get lost, even on familiar roads, or have trouble staying centered in your lane.
  - 4. You or your loved ones have anxieties around your driving.** Family and friends may express their worries, or you might feel nervous when behind the wheel.
- However, there are proactive steps you can take to continue safely driving. They include:**
- 1. Taking charge of your wellbeing by prioritizing your health.** Schedule regular check-ups with your healthcare team to ensure you are fit to drive safely, and make sure to stay on top of any optometry appointments to keep your vision as sharp as possible.
  - 2. Choosing a vehicle that suits your needs and can provide any aids to assist your driving.** Decide whether manual or automatic transmission, advanced safety systems (such as rearview cameras, blind spot detection, and lane departure warnings), and/or power brakes are the right options for you. And remember, regardless of the car you choose, make sure it is in safe condition by following the maintenance schedule suggested by the manufacturer.
  - 3. Staying up to date with your driving skills and knowledge of the road.** Visit a driver licensing office to obtain resources like ICBC's Learn to Drive Smart or Tuning Up for Drivers, or download them digitally at <https://bit.ly/ICBCLearnToDriveSmart> and <https://bit.ly/ICBCTuningUpForDrivers>. You may also consider enrolling in a driving course with a private instructor. A third-person perspective can shed light on ingrained habits you may not even be aware of, allowing you to make adjustments and develop new, safer habits.
  - 4. Developing defensive driving techniques.** Ensure you maintain a safe distance from the vehicle in front of you, pay extra attention at intersections, and always use timely turn signals before making a lane change.
  - 5. Recognizing your limitations.** It is essential to monitor your driving abilities for your own safety and the safety of others. If you feel uncomfortable in specific driving situations, be honest with yourself. Keep an eye out for warning signs such as health issues (conflicting medications, vision or hearing problems, reflexes and mobility issues, memory problems) or recurring road-related problems (difficulty making decisions, drifting, braking issues, receiving driving violation tickets).

While the thought of voluntarily relinquishing your license may bring up worries of losing your independence, especially for those in rural areas, this does not have to be the case. By using services like public transport, which may have lower fare prices for seniors, and taxis/ride sharing, you can continue to safely get around. Grocery stores, libraries, restaurants, and many other establishments in your community also usually offer delivery services at low or no cost.



And for those who have been drivers all their lives, they may not have considered how relaxing it can be to be a passenger, free from the burdens of navigating traffic and encountering stressful driving situations. There are cost-saving benefits, too – the average annual cost of operating a car in Canada is \$8,800 (*Reviewlution, 2023*)!

The decision to drive does not need to be all-or-nothing. Some individuals find that they feel safer driving in the daytime and avoid driving at night when lighting conditions are less favourable. Others might avoid highways but feel comfortable taking a short daily trip to a nearby store. Work with your doctor and loved ones to determine how and when you should drive, as well as when it might be a good idea to considering hanging up your car keys.

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## ADDITIONAL RESOURCES

- **Province of British Columbia**  
Sample DMER: <https://bit.ly/DMERSampleBC>



## Hypomimia (facial masking) and its impact on social wellbeing

Parkinson's disease (PD) is commonly recognized by its motor symptoms, such as tremor and slowness of movement. However, even though non-motor symptoms, like hypomimia, also known as facial masking, are not often publicly understood as being associated with PD, they can significantly impact an individual's social interactions and overall wellbeing. Hypomimia refers to the reduced ability to display facial expressions due to muscle stiffness and rigidity in the face. Individuals with hypomimia often experience a decrease in spontaneous facial movements, making it difficult to convey emotions and social cues effectively. The symptom affects various facial muscles, including those responsible for smiling, frowning, and raising the eyebrows. This can be especially challenging when paired with speech changes commonly associated with PD, such as reduced voice volume (*Gunnery et al., 2016*).

Hypomimia can manifest in the very early stages of the disease, often becoming noticeable years before a clinical diagnosis. Despite being one of the earliest symptoms, it is frequently misinterpreted as a lack of interest by an individual's social circle or misdiagnosed as depression by physicians. The unique characteristics of hypomimia make it more challenging to evaluate compared to other symptoms of Parkinson's disease. Unlike many PD symptoms, hypomimia is typically not asymmetric and exhibits variability in response to treatments like levodopa and Deep Brain Stimulation (DBS). Additionally, the lack of objective measurement tools further complicates its accurate assessment (*Maycas-Cepeda et al., 2021*). People with PD experiencing hypomimia are more prone to heightened interpersonal difficulties, including emotional distress, frustrations within social relationships, and feelings of disconnection from others (*Clark et al., 2008*).



### The impact on social interactions

Social interactions are built on a complex web of verbal and non-verbal communication. Facial expressions play a crucial role in conveying emotions, intentions, and social cues, enabling individuals to connect and empathize with one another. However, for those with hypomimia, these essential non-verbal cues are diminished, leading to various challenges in social interactions. Research has found a significant association between hypomimia and social wellbeing (*Gunnery et al., 2016*), including the following issues:

- 1. Emotional disconnect:** Hypomimia can create an emotional disconnect between individuals with PD and their peers, as the inability to display facial expressions makes it challenging for others to gauge their emotional state accurately. It can be frustrating when others misinterpret a lack of facial expression as sadness or disinterest. This can also lead to misunderstandings, social awkwardness, and reduced emotional bonding (*Clark et al., 2008*).

- 2. Impaired communication:** Facial expressions contribute significantly to effective communication. When individuals with PD experience hypomimia, their ability to convey subtle nuances and intentions is compromised. This can result in misinterpretations, confusion, and difficulties in establishing rapport during conversations. Research studies also show that individuals with hypomimia often experience challenges in recognizing and interpreting others' facial expressions, particularly negative emotions, leading to further communication challenges and reduced empathetic responses (Clark et al., 2008).
- 3. Social isolation:** Hypomimia can lead to social isolation, as others may find it difficult to relate to someone who appears less responsive or engaged. Over time, this can cause individuals with PD to withdraw from social activities, impacting their overall quality of life. People with Parkinson's who experience more severe hypomimia have reported lower levels of social participation, reduced social support, and consequently decreased social wellbeing (Gunnery et al., 2016).
- 4. Negative perceptions:** Unfortunately, hypomimia can lead to negative perceptions and stigmatization. Due to lack of facial expressiveness, others may mistakenly assume that individuals with PD are uninterested, bored, or lacking in cognitive abilities. These misconceptions can fuel self-consciousness regarding symptoms and a fear of embarrassment, resulting in the creation of social barriers that further isolate individuals with Parkinson's disease (Prenger et al., 2020).
- 5. Relational changes with carepartners/caregivers:** The psychological effects of hypomimia also impact the relationship between the individual with Parkinson's and their carepartner/caregiver. According to a research study, carepartners reported challenges in interpreting and understanding the emotional state of loved ones with PD due to their reduced facial expressiveness. This indicates that the impact of hypomimia extends beyond the individual with PD, leading to communication difficulties and emotional disconnect, as well as a potentially compromised social wellbeing of both the person with PD and their carepartner (Gunnery et al., 2016).



## STRATEGIES FOR COPING

While hypomimia poses several challenges, there are strategies that individuals with PD and their loved ones can employ to mitigate its impact on social interactions, such as:

- 1. Education and awareness:** A lack of awareness can act as a barrier to satisfying close relationships. Educating family members, friends, and the community about hypomimia can help dispel misunderstandings and reduce stigma. By promoting greater awareness, individuals touched by Parkinson's can encourage empathy, patience, understanding, and inclusivity (*Gunnery et al., 2016*).
- 2. Compensatory strategies:** Individuals with PD can learn compensatory strategies to enhance non-verbal communication. These may include exaggerating facial expressions where possible, using hand gestures, or employing verbal cues to convey emotions effectively. One study found that carepartners of people with Parkinson's said that asking their partner clarifying questions about their emotional state helped them better navigate social interactions in the presence of hypomimia. They also relied on their familiarity with the person to interpret emotions based on other non-verbal cues or contextual information (*Gunnery et al., 2016*).
- 3. Supportive environments:** Creating supportive environments that encourage open communication and understanding can make a significant difference. Friends, family, and colleagues can be educated about PD and its associated symptoms to foster an inclusive and accepting social atmosphere. If you feel comfortable and have a supportive network, try explaining your difficulty with muscle control and expression to your loved ones, as this can help them understand you better and increase their awareness of Parkinson's. Discussing the challenges posed by hypomimia can help bridge the communication gap and strengthen emotional connections (*Wootton et al., 2018*).

## 4. Speech and occupational therapy:

There are no known effective treatments designed to alleviate hypomimia in Parkinson's specifically. However, research has found that speech and occupational therapy can assist those with PD in improving facial muscle control and enhancing non-verbal communication. These therapies focus on exercises and techniques that target facial expression and help individuals regain some of their natural expressiveness. The Lee Silverman Voice Treatment (LSVT LOUD®), originally designed for addressing speech-related issues in PD, has been found to have an additional positive effect of improving facial expressiveness in individuals experiencing hypomimia (*Dumer et al., 2014*).

Research on hypomimia in Parkinson's disease highlights the importance of implementing interventions and providing support to tackle the social obstacles that can arise as a result of the symptom. By doing so, we can strive toward enhancing the overall quality of life for those affected by facial masking.

Recognizing the multifaceted impact of hypomimia on social interactions is crucial for individuals with PD. It is important to be aware that hypomimia is a distinct symptom of PD and not a reflection of the individual's true emotions. By promoting education, empathy, and support, individuals with Parkinson's can enhance their social interactions, emotional connections, and overall quality of life, despite the challenges posed by hypomimia.

It is important to remember that you are not alone in facing the challenges of hypomimia. Many individuals with PD experience similar difficulties, and resources are available to help navigate these obstacles. Seeking support from healthcare professionals, support groups, and online communities can provide a sense of connection, understanding, and practical advice.

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# World Parkinson Congress

## Highlights

The World Parkinson Congress (WPC) is a triennial global gathering that provides a diverse range of participants with a platform to come together and engage in meaningful discussions and collaboration. The Congress facilitates learning and debates surrounding the latest scientific breakthroughs, medical advancements, and comprehensive care practices related to Parkinson's disease (PD) among scientists, clinical researchers, healthcare professionals, individuals living with Parkinson's, and others.

What sets the WPC apart from other scientific gatherings is its inclusive nature, aiming to bring together all members of the PD community. The event fosters a conducive environment for the discovery of a cure and the development of optimal treatments by encouraging collaboration among scientific, clinical, rehabilitation, and advocacy communities.

The 6<sup>th</sup> World Parkinson Congress took place from July 4 – 7 in Barcelona, Spain. WPC 2023 saw an impressive attendance, with delegates representing various professions: over 900 medical doctors and researchers, 450 registered nurses, rehabilitation therapists, and other clinicians, along with 685 people living with PD, and 260 carepartners/family members.



*Pictured: Representatives of Parkinson Society BC*

In July 4, the Congress commenced with a day of educational courses, followed by an inspiring opening ceremony showcasing the resilience of the Parkinson's community through stories of carepartners, people with PD, and healthcare professionals. The ceremony featured performances by the WPC Choir and dancers, including a special video message from Sir Paul McCartney, speaking about his personal experience with a friend diagnosed with the disease.

Representatives from Parkinson Society BC (PSBC), including staff and community members, were present at the event and found immense joy in connecting with fellow participants. They took the opportunity to re-establish connections on both local and international scales, especially after experiencing limited in-person interactions because of the COVID-19 pandemic.

Representatives enjoyed engaging in discussions in small and intimate settings, where they addressed specific clinical issues that arise in their daily work. They appreciated hearing diverse perspectives and found valuable takeaways to implement in their practices.

"I am deeply touched by the people that I met and the stories that unfolded," said PSBC Board Treasurer, Martie Rose Mendoza. "It was a great bonding experience for us." PSBC community members also reported particularly enjoying Tightrope Impro Theatre's PD Performance Troupe's sold-out show: Tremors and Triumphs. The show at WPC 2023 marked the Troupe's first in-person performance, after a prolonged period of virtual interactions due to the pandemic. "The wit and spontaneity of the Impro Troupe was definitely something to be admired," said PSBC neuro physiotherapist, Shelly Yu. "It really showcased the importance of friendship, community, and laughter when navigating a chronic illness."

# Poster Presentations

from PSBC

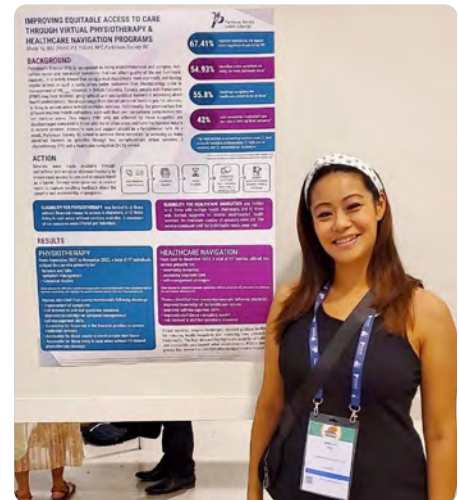
## BRIDGING THE GAP BETWEEN CLINICAL & SOCIAL CARE: SOCIAL PRESCRIPTION INITIATIVES

People living with Parkinson’s disease experience isolation and loneliness, resulting in reduced quality of life. Social symptoms, such as facial masking, difficulty with expressing emotion in communication, and recognizing emotional cues in others, can coexist with physical and psychological symptoms. These symptoms can cause people with PD to self-isolate. Despite the focus on pharmacological treatment as the gold standard for PD care, PSBC seeks to improve the quality of life of people with Parkinson’s by adopting a biopsychosocial approach. Through social prescription initiative programs, PSBC aims to bridge the gap between clinical and social care, addressing both the physical symptoms and social consequences of PD.



## IMPROVING EQUITABLE ACCESS TO CARE THROUGH VIRTUAL PHYSIOTHERAPY & HEALTHCARE NAVIGATION PROGRAMS

Parkinson’s disease is recognized as being multidimensional and complex, with various symptoms that can affect quality of life and functional capacity. It is widely known that using a multidisciplinary team approach offers better outcomes than pharmacology alone in management of PD. However, in British Columbia, people with Parkinson’s may face financial, geographical, and sociopolitical barriers in accessing allied healthcare professionals. Access to care and support should be a fundamental right. As a result, Parkinson Society BC aimed to address these inequities by removing as many identified barriers as possible through two complimentary virtual services: a physiotherapy (PT) and a healthcare navigation (HCN) service.



## PIVOTING TO A VIRTUAL WORLD: HOW PARKINSON SOCIETY BRITISH COLUMBIA INCREASED IMPACT & REACH TO THE PARKINSON’S COMMUNITY DURING THE 2020 PANDEMIC

Historically, Parkinson Society BC provided primarily in-person services, such as regional and provincial conferences, speech and swallow workshops, counselling, support groups, and exercise campaigns. With the 2020 COVID-19 pandemic restrictions on all in-person gatherings, PSBC’s various in-person events and services were cancelled. PSBC problem-solved the halted provision of essential support services that the Parkinson’s community depends on to live well. Although a hindrance initially, the pandemic provided a unique opportunity to pivot service delivery onto a virtual platform.



# Environmental Contributions to Parkinson's Disease

**The following is a summary of one of the sessions from the World Parkinson Congress we wanted to share with our community:**

Beate Ritz, Briana De Miranda, and Ray Dorsey presented on the current understanding of the role of pesticides and toxic chemicals with respect to PD. They also discussed prevention in the context of environmental exposure.

While the exact cause of Parkinson's remains unknown, there is increasing evidence suggesting that environmental toxins play a significant role. Recent research has revealed a link between air pollution and the development of PD and other neurodegenerative diseases. Studies have shown that air pollution is the sixth leading preventable cause of death globally, and approximately 40% of the United States still breathes unhealthy air. Shockingly, 95% of the world's population is exposed to air pollution levels above the guidelines set by the World Health Organization (WHO).

Additionally, certain pesticides, including paraquat, have been associated with a 150% increased risk of PD. Its usage, especially in agriculture-heavy regions like California (a major source of British Columbia's produce), has doubled in recent years. The Environmental Protection Agency (EPA) in the United States says, "one sip can kill," but has not yet banned this pesticide. However, in February 2023, there was a significant development regarding the use of paraquat-containing products in Canada. The only product containing paraquat, known as Gramoxone®, was discontinued and is no longer sold or permitted. However, there are lingering worries about the residual effects for individuals previously exposed to this toxic chemical.

The global use of pesticides, in general, has seen a disturbing trend, having doubled in the past two decades. Another toxicant, Trichloroethylene (TCE), has been found to be associated with a 500% increased risk of Parkinson's. Despite this, the US and Canada continue to allow its use in various industrial

applications, leading to thousands of contaminated sites and a continuing rise in global usage at approximately 3% per year.

Encountering paraquat and other toxic pesticides is possible in specific industries, but it is unlikely you will find them in your garage or available for purchase in stores.

**However, those employed in industries that use these chemicals should take precautions to ensure their safety, such as the following:**

*(Tips were adapted from Parkinson Canada)*

- Familiarize yourself with hazardous materials labeling through Workplace Hazardous Materials Information System (WHMIS) training and carefully check product labels before use.
- Follow workplace procedures and safety requirements related to working with chemicals, and communicate any concerns you may have. Your rights as an employee are protected by British Columbia's WorkSafe BC program.
- Wear appropriate personal protective equipment like gloves, masks, and goggles as indicated on the pesticide label or provided by your employer.
- Consider weather conditions before applying pesticides outside, as wind, heat, and rain can intensify their impact.
- Thoroughly wash your hands after pesticide use, even if you wore gloves during application.
- Avoid eating, drinking, or smoking while handling pesticides to prevent direct ingestion.
- Refrain from touching your face or eyes until you've washed your hands after working with pesticides.
- Change out of the clothes used during pesticide application and wash them separately from other clothing.
- Dispose of pesticide containers properly following the instructions on the label to avoid unnecessary exposure after use.
- Contact your city office for guidance on proper disposal if you have leftover pesticides with no plans for future use.
- For more comprehensive information on handling pesticides safely, refer to the Canadian Government's "Use Pesticides Safely" guidelines, found at <https://bit.ly/canada-pesticides>.

# Newsworthy

## Upcoming Education & Exercise Events

*Tuesdays, Aug 1 – Sept 26*

### **Move with Confidence: Parkinson's Fitness (Level 1)**

 Online

In this introductory class, experienced instructor Janey Enmil will guide participants through a series of exercises and activities that focus on improving mobility, balance, strength, and coordination.

*Mondays, Aug 21 – Sept 18*

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

 Online

Popping, a form of dance originating in the late 1970s in California, involves rhythmic muscle contractions to the beat. This class will use this dance form as therapy to improve physical condition in those with Parkinson's.

*Wednesday, Sept 13*

### **Navigating Employment with Young Onset Parkinson's: Legal Rights, Disclosure, & Accommodations**

 Online

Expand your knowledge about your legal rights, the benefits and risks of disclosure, and explore effective strategies for securing workplace accommodations. The session will also cover practical tips and advice on communication techniques, self-advocacy, and navigating disclosure conversations.

*Saturday, Sept 16*

### **Communication and Swallow Workshop (Victoria)**

 Lambrick Park Church

Led by Jasmine Cload, a registered speech-language pathologist, this workshop will address communication and swallowing difficulties in individuals with Parkinson's and other neurological conditions. Member pricing available.

*Twice a week (Wed & Fri), starting Sept 20*

### **Painting & Play: Expressive Arts Therapy for People with Parkinson's Disease**

 Online

This six-week long virtual series will focus on expressive art therapy for emotional wellbeing, self-confidence, belonging, and creative self-management tools. Expressive art interventions will include vision boards, watercolour, mindfulness art, and creative movement exercises, followed by facilitated discussions.

*Thursdays, Sept 21 – Oct 26*

### **SongShine**

 Online

This program harnesses the power of the brain, breath, and emotion to reclaim voices. Joani Bye will engage participants using singing, breath work, diction, articulation, and creative imagination exercises to strengthen voices affected by Parkinson's or other neurological challenges.

*Tuesdays, Oct 3 – Nov 28*

### **Rock Steady Boxing with Doug (Level 2/3)**

 Online

People living with Parkinson's will experience a total workout for both their mind and body through this class, as it incorporates cardio, strength, balance, hand-eye coordination, and speed.

## Thank you to Our Fundraisers & Donors

Longtime supporters, Me-n-Ed's Pizza Parlours, held their annual golf tournament, resulting in a generous \$5,000 donation to the Society. Thank you to the team at Me-n-Ed's, the attendees, and the volunteers for making this possible.

A big thank you to everyone who attended and supported the 7th annual Full Throttle ride, including a car and motorcycle show & shine. We are very grateful for the ongoing efforts of Jim Smerdon and his supporters, which led to over \$13,000 in donations!

This year's Elk Valley Golf Tournament was sold out! Thanks to Adam Toner and his team for their continued support of the Society with this event raising over \$19,000 in 2023!



# Advancing Parkinson's Treatment:

## Health Authorities Continue Allied Healthcare Professional Funding



Following Parkinson Society BC's (PSBC) strategic initiative to fund pilot projects that showcased the invaluable role of Allied Healthcare Professionals (AHCPs) in supporting the care of people with Parkinson's disease, we're pleased to announce impactful changes in provincial healthcare funding.

These pilot projects, financially backed by PSBC, were designed to underscore the necessity and efficacy of AHCPs in providing critical Parkinson's care. Recognizing the transformative impact of these pilot projects and AHCPs, both the Interior and Island Health Authorities have now committed to budgeting for the continued funding of the AHCP roles.

Through a multidisciplinary approach, AHCPs have proven instrumental in elevating the quality of life for Parkinson's patients, simultaneously easing strain on the healthcare system by reducing unnecessary hospital admissions.

In the Central Okanagan, where Parkinsonism has the highest incidence in the province, the Interior Health Authority will continue support for a part-time physiotherapist, speech-language pathologist, and social worker, providing a third

of the salary costs. On Vancouver Island, with over 2,650 Parkinson's patients, Island Health's commitment will fund one third of a full-time speech-language pathologist.

PSBC also continues to financially support a pilot project with the Vancouver Coastal Health Authority. This project supports the UBC Movement Disorder Clinic with a part-time occupational therapist and a part-time speech-language pathologist. PSBC hopes that following a successful evaluation, the health authority will recognize the substantial benefits of AHCPs and transition the supportive funding from PSBC into their regular budget.

While the transition from pilot to partial funding by the health authorities is a celebratory milestone, PSBC's mission remains focused on persisting in our efforts to expand access to AHCPs across the province, advocate for necessary policy changes, and ensure comprehensive care.

We express heartfelt thanks to everyone involved in these efforts. Together, we strive towards an increasingly supportive and inclusive landscape for all impacted by Parkinson's in British Columbia.

# PARKINSON SUPERWALK®

Join us for Parkinson Society British Columbia's (PSBC) largest fundraising event of the year, Parkinson SuperWalk!

Beginning the weekend of September 9 and 10, incredible British Columbians in more than 20 communities throughout the province will walk together to help give hope to approximately 15,000 people in BC living with Parkinson's disease. Funds raised in BC through this event help PSBC continue to grow programs and services, expand advocacy efforts, and increase investment in innovative research.

## 100 MILE HOUSE

Centennial Park  
Saturday, September 9

## CHILLIWACK

The Landing Sports Centre  
on Spadina  
Saturday, September 9

## COMOX VALLEY

Virtual Walk  
Saturday, September 9 or 10

## KAMLOOPS

Riverside Park  
Saturday, September 9

## KELOWNA

Waterfront Park  
Saturday, September 9

## NEW WESTMINSTER

Moody Park  
Saturday, September 9

## PARKSVILLE/ QUALICUM BEACH

Rathrevor Beach Provincial Park  
Saturday, September 9

## PITT MEADOWS/ MAPLE RIDGE

Hammond Community Centre  
Sunday, September 10

## PRINCE GEORGE

Lheidli T'enneh Memorial Park  
Saturday, September 9

## VANCOUVER

Stanley Park/Ceperley Park  
Playground  
Sunday, September 10

## VERNON

Polson Park  
Saturday, September 9

## VICTORIA

Hamsterly Beach Park  
Saturday, September 9

## WHITE ROCK

Kintec Store (Parking Lot)  
Sunday, September 10

TO REGISTER OR DONATE, VISIT

[WWW.PARKINSON.BC.CA/SUPERWALK](http://WWW.PARKINSON.BC.CA/SUPERWALK)

## Join the journey of discovery!

Contribute to enhancing lives of those affected by Parkinson's by participating in groundbreaking research studies. Your involvement paves the way for a brighter future.

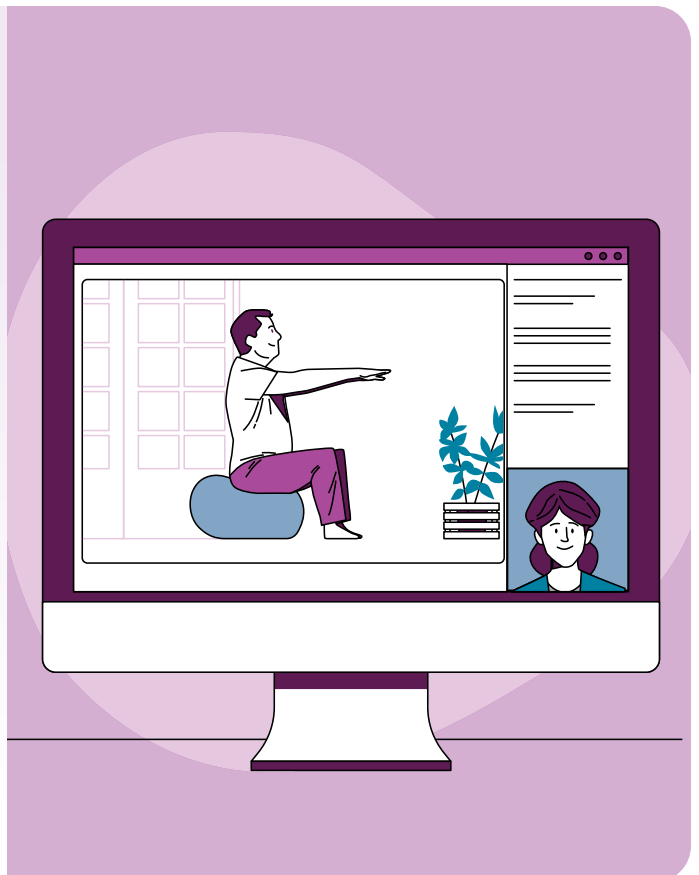
Visit [www.parkinson.bc.ca/research-recruitment](http://www.parkinson.bc.ca/research-recruitment) and make a meaningful impact today.



## Did you know?

Parkinson Society BC is proud to offer a virtual physiotherapy service! This service is available by phone or video-conferencing sessions to help individuals access Parkinson's-specific therapies. For people meeting certain criteria, virtual physiotherapy is available free of charge.

Visit [www.parkinson.bc.ca/virtualphysio](http://www.parkinson.bc.ca/virtualphysio) to learn more!



# Stay Connected to the Parkinson's Community

It's that time of year again! Renew your membership with Parkinson Society British Columbia and continue to be part of our friendly, caring, and supportive community.

For only \$25, you will receive an annual membership for you and your household, valid until December 31, 2024. *Reasons to renew your membership:*

## Get Discounts

Your membership provides you with great discounts on events that are not to be missed!

## Be Heard

Vote at our Annual General Meeting and add your voice to the community to garner support from donors, sponsors, and politicians.

## Stay Informed

Get the latest information on research, medication, caregiving, exercise, wellbeing, and nutrition when you receive our quarterly magazine, Viewpoints, and other publications.

## Gain Support

Link to our provincial network of over 50 support groups, and speak with our knowledgeable and compassionate staff.

[www.parkinson.bc.ca/membership](http://www.parkinson.bc.ca/membership)



**Questions?** Contact Susan Atkinson at 1-800-668-3330 ext 263 or [satkinson@parkinson.bc.ca](mailto:satkinson@parkinson.bc.ca)



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