

## SPECIAL NOTICE

*In response to the global outbreak of COVID-19, Parkinson Society BC (PSBC) staff are working remotely until further notice. We will continue to offer programs and services in alternate formats. For the most up-to-date information, visit this web page: [www.parkinson.bc.ca/coronavirus](http://www.parkinson.bc.ca/coronavirus). If you have any questions, please contact us at [info@parkinson.bc.ca](mailto:info@parkinson.bc.ca).*

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## UPCOMING EVENTS

- **Balance Exercise Series** | Tuesdays, May 3 – 31  
Learn more & register: <https://bit.ly/balanceexercisepd>
- **Rock Steady Boxing with Doug Pickard** | Wednesdays, May 4 – 25  
Learn more & register: <https://bit.ly/rocksteadypd22>
- **Global Symposium Series**
  - **Breakthrough Therapies for Parkinson's** | Wednesday, May 4  
Learn more & register: <https://bit.ly/globalsymposium-breakthrough>
  - **Gyro-Kinetics for Parkinson's** | Wednesday, May 11  
Learn more & register: <https://bit.ly/globalsymposium-gyrokinetics>
  - **Personality & Behaviour Changes** | Friday, May 20  
Learn more & register: <https://bit.ly/globalsymposium-personality>
- **May Open House** | Tuesday, May 10  
Learn more & register: <https://bit.ly/openhouse-may>
- **Caregiving Series**
  - **Part I: Panel Talk: Our Caregiving Stories** | Friday, June 3  
Learn more & register: <https://bit.ly/caregiving-stories>
  - **Part II: Legal Considerations & Long-Term Health Planning** | Wednesday, June 8  
Learn more & register: <https://bit.ly/caregiving-legalandhealth>
  - **Part III: Caregiving Stages: Learn Optimism, Discover Hope** | Wednesday, June 15  
Learn more & register: <https://bit.ly/caregiving-stories>

- **Voice Aerobics®** | Thursdays, June 16 – 30  
Learn more & register: <https://bit.ly/voiceaerobicspd>
  - **Regional Conference: Kelowna** | Saturday, June 18  
Learn more & register: <https://bit.ly/kelownaregionalconference22>
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### UPCOMING FUNDRAISING EVENTS

#### *Champions for Parkinson's*

- **Full Throttle** | Sunday, May 29  
Full Throttle is a relaxed and scenic ride or drive from Vancouver to Squamish along the Sea to Sky highway. Funds raised from this event will benefit Parkinson Society British Columbia's (PSBC's) programs, services, advocacy efforts and contributions to research for the 15,000 British Columbians living with Parkinson's disease. Learn more and register at [www.parkinson.bc.ca/fullthrottle](http://www.parkinson.bc.ca/fullthrottle).
- Donate a Car Canada: Ongoing (read more: <http://bit.ly/2ORTuJn>)

#### *We're looking for more Champions!*

Do you want to help fund research, grow support networks, and improve quality of life for those living with Parkinson's disease (PD)? Become a Champion for Parkinson's and plan your own independent community fundraising event! Contact Alicia Wrobel at [awrobel@parkinson.bc.ca](mailto:awrobel@parkinson.bc.ca) or 1-800-668-3330 ext. 237

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### TIP JAR

The Tip Jar is where we share advice from Parkinson's community members. This month, we share advice on accessibility and digital devices.

- Grant from the Vancouver Support Group advises people with PD to use a stylus pen when using a touch screen on iPads, tablets, or smart phones. It makes using digital devices a lot easier.

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Do you have any tips or tricks that you would like to share with the Parkinson's community? These can be tips from something that works well, to eating and dressing, to getting out of bed or travelling! All tips and tricks are welcome! Please share your ideas at [info@parkinson.bc.ca](mailto:info@parkinson.bc.ca).

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## NEWS & ANNOUNCEMENTS

### **Updated provincial health orders regarding in-person support group meetings**

As per the updated COVID-19 restrictions, PSBC will resume in-person support groups for those who sign the indoor meeting agreement. Support groups may still choose to access our Zoom accounts if they prefer to remain virtual. For facilitator inquiries, please email Liz Janze, *Education & Support Services Coordinator*, at [ljanze@parkinson.bc.ca](mailto:ljanze@parkinson.bc.ca) or call 1-800-668-3330 ext. 228.

### **New! Healthcare Navigator role**

The Society has hired a new part-time staff member who will be available to provide guidance for navigating the complexities of the healthcare system. You can access this assistance by contacting us at [info@parkinson.bc.ca](mailto:info@parkinson.bc.ca). A staff member will work with you to assess your needs.

### **Support the expansion of the Deep Brain Stimulation (DBS) program in BC**

In 2019, the BC Ministry of Health promised a second neurosurgeon to help reduce waitlist times for DBS surgeries. The waitlist to see Dr. Christopher Honey for initial DBS assessment is now up to four years. Once approved for surgery, the wait is up to an additional 12 months.

We need the BC Ministry of Health to follow through on their promise. TAKE ACTION and support our letter writing campaign today at [www.parkinson.bc.ca/dbs](http://www.parkinson.bc.ca/dbs).

### **Volunteer as a community organizer for Parkinson SuperWalk**

To make our largest fundraising event possible, we are seeking walk coordinators across five communities (Abbotsford, Comox Valley, Kamloops, Prince George, and Richmond). Learn more and apply at [www.parkinson.bc.ca/sworgrecruit](http://www.parkinson.bc.ca/sworgrecruit).

***Step by Step walk leaders needed***

Step by Step is a 12-week walking program aimed at improving physical fitness to combat the symptoms of PD. To learn more or start a group in your community, please visit

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

***Class action lawsuit: Gramoxone® (paraquat)***

Gramoxone® is an herbicide used to control weeds and grasses with an active ingredient called paraquat. It is alleged that paraquat exposure is linked to Parkinson's disease (PD). Law firm Siskinds Desmeules has filed proposed class action lawsuits on behalf of all Canadians who have been diagnosed with PD after using and/or being exposed to Gramoxone®, since July 1, 1963. To learn more, visit [www.parkinson.bc.ca/gramoxoneclassaction](http://www.parkinson.bc.ca/gramoxoneclassaction).

***COVID-19 vaccination***

Throughout 2022, COVID-19 vaccines will be made available to all Canadians. Read Parkinson Society BC's COVID-19 Vaccination Statement for more information about the vaccine – including how it works, how it will be distributed, and considerations for people with Parkinson's – at

[www.parkinson.bc.ca/covid-vaccine](http://www.parkinson.bc.ca/covid-vaccine).

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***DISCUSSION TOPIC: Speech & swallowing******Discussion Questions***

1. How has Parkinson's affected your speech and swallowing abilities in your everyday life?
2. What are some practices you are actively doing to improve your speech and swallowing?

Every year, Speech-Language & Audiology Canada dedicates the month of May to raising awareness about communication health. Our ability to communicate gives us the freedom to express ourselves and connect with the world around us. However, for people with Parkinson's disease (PD), changes in speech and swallowing are common, with up to 90% of people with PD

experiencing challenges with communication. Other motor symptoms, such as a lack of facial expression and slouched posture, can also contribute to changes in speaking and communicating (The Michael J Fox Foundation, n.d.). Sometimes, people with Parkinson's may speak quietly, portray little to no emotion, and slur words, which can be frustrating when communicating their needs and wants.

It is not uncommon for speech and swallowing difficulties in PD to occur simultaneously, as many of the same muscles used for speaking are also used for swallowing. Parkinson's symptoms can affect respiration, voice production, and articulation due to the slowing of the muscles that produce the outcome of our speech (Matsuo & Palmer, 2008). Muscles in the lips, tongue, throat, and larynx (voice box) all work together to aid in our ability to speak and swallow, and changes within these muscles can occur at any time in those living with the disease.

### **How do I know if my speech and swallowing are changing?**

Noticing changes in how you speak and swallow may not always be initially obvious; however, being mindful of your body and how you feel is key. If you are experiencing any of the challenges below, it may be valuable to seek treatment from your doctor or a speech-language pathologist (SLP):

Changes in speech can look like:

- Others around you having difficulty hearing your voice when speaking
- Feeling the need to strain your voice to produce speech
- A softer, lower, and monotone voice
- Running out of breath when speaking
- Decreased facial expression
- Slurring in your speech

Whereas changes in swallowing can look like:

- Food getting 'stuck' in the throat
- Coughing and/or choking when eating and drinking

- Difficulty initiating swallowing
- Sudden and unexplained weight loss
- Slower eating
- Nasal regurgitation

For a comprehensive self-evaluation tool to help you evaluate perceived problems with speech, swallowing, and saliva control, please see the The Radboud Oral Motor Inventory for Parkinson's disease (ROMP) at <https://bit.ly/radboudsinventory>.

### Treatment for changes in speech and swallowing

A speech-language pathologist is an important care provider during your Parkinson's journey, helping support your quality of life and communication. Local hospitals, rehabilitation centres, and movement disorder clinics within BC have SLPs ready to provide inpatient and outpatient services. [The College of Speech and Hearing Health Professionals of BC's](#) (CSHBC) website is a great resource to find an SLP in your area. [The BC Association of Speech-Language Pathologists](#) is another reliable way to find professional resources in your geographical region.

To evaluate changes in swallowing, a doctor may order a test that X-rays you while you swallow foods and liquids of different kinds. This test then shows where the issues are in the mouth or throat, and if the food and liquids are moving into the stomach or the airway (The Michael J. Fox Foundation, n.d.). The gold standard evaluation tool is the Barium Swallow, which includes a video X-ray performed by an SLP and radiologist to detect exact locations and characteristics of difficulties in the swallowing mechanism.

Some recommendations from an SLP may include:

- **[The Lee Silverman Voice Treatment \(LSVT\)](#)**: This is the gold standard for speech therapy for those living with PD. LSVT helps with exaggerating speaking and swallowing. An SLP may use this treatment to help you swallow better (Parkinson's Foundation, n.d.)
- **Expiratory Muscle Strength Training (EMST)**: In this form of therapy, a device works the respiratory muscles, strengthening and improving cough and swallowing mechanisms

- **Modifying your diet:** Adjusting the liquids and solids in your diet can be extremely beneficial. Changes, such as thickening liquids for those finding liquids getting caught in the airways or taking bigger or smaller sips and bites, can aid in difficulties with swallowing (Parkinson's Foundation, n.d.)

There are many additional ways you can take charge of your speech and swallowing abilities in your daily life, such as:

- Using technology that aids in voice and communication. There are several apps available for download on your smartphone, such as Speak Up for Parkinson's, Voice-O-Meter, iParkinson's, and Speech Easy
- Keeping writing materials, like a notepad and pen, on hand with you at all times. This is an easy and effective way to communicate without speaking
- Getting involved in the arts. Acting lessons, choirs, and singing lessons are all effective ways to not only strengthen your voice muscles, but also your confidence
- Bookmarking specific times in your day when your speech is at its best, and planning your social activities around these times, if possible
- Taking pauses while speaking and eating. It's okay to move at a slower pace
- Resting your voice when you feel it is being strained or tired
- Practicing hard swallowing in between meals
- Integrating easier-to-eat foods into your diet, such as softer, more liquid-based meals

Speech and swallowing difficulties can significantly impact the lives of those living with PD. Fortunately, with the help of your medical team, it is possible to manage speech and swallowing issues and live a fulfilling life.

### ***Additional Resources***

Communication and Swallowing | Booklet | [bit.ly/communicationandswallowbooklet](https://bit.ly/communicationandswallowbooklet)

Enhancing Communication | Helpsheets | [bit.ly/enhancingcommunication](https://bit.ly/enhancingcommunication)

Language Impairment | Jamie Russell, SLP | Video |

<https://www.youtube.com/watch?v=kqICdiYrqJo&list=PLTORB8dLB6L9LzsF7xqAoJfswSuBDEL5&index=3>

Communication and Swallowing in Parkinson's Disease | Sherri K Zelazny | Video |

<https://www.youtube.com/watch?v=yWhWCyuV26I>

Swallowing and Saliva Management | Jasmine Cload, SLP | Video |

<https://www.youtube.com/watch?v=eeqdBZX8u9c>

Voice and Speech | Jasmine Cload, SLP | Video |

<https://www.youtube.com/watch?v=09MbprPp30c>

Language, Cognition, Communication, and Technology | Jasmine Cload, SLP | Video |

<https://www.youtube.com/watch?v=CSSbTzqVYRU>

Voice | Helpsheet | [bit.ly/voiceandPD](http://bit.ly/voiceandPD)

### **Sources**

Matsuo, K., & Palmer, J. B. (2008). Anatomy and physiology of feeding and swallowing: normal and abnormal. *Physical medicine and rehabilitation clinics of North America*, 19(4), 691-707.

Parkinson's Foundation. (n.d.). Speech & Swallowing Problems.

<https://www.parkinson.org/Understanding-Parkinsons/Symptoms/Non-Movement-Symptoms/Speech-and-Swallowing-Problems>

The Michael J. Fox Foundation. (n.d.). Speech & Swallowing Problems. The Michael J. Fox Foundation for Parkinson's Research | Parkinson's Disease.

<https://www.michaeljfox.org/news/speech-swallowing-problems>