

SPECIAL NOTICE

In response to the global outbreak of COVID-19, Parkinson Society BC has been taking proactive measures to manage the potential for transmission. As such, we have made the decision to close our office. Staff will be working remotely until further notice. We will continue to offer programs and services in alternate formats.

All calls will be directed to voicemail, with staff checking their messages frequently. We will be answering all queries in order of priority. Please note that calls may be returned from unfamiliar phone numbers during this time. If you wish to contact our staff directly via email, individual contact information is available in our staff listings at www.parkinson.bc.ca/staff.

For the most up-to-date information, please visit this PSBC web page: www.parkinson.bc.ca/coronavirus. If you have any questions, please contact us at info@parkinson.bc.ca. We thank you for your patience during this time.

UPCOMING EVENTS

Parkinson Society British Columbia endeavours to make attendance at events accessible to all who may benefit. The Society may be able to subsidize attendance fees for those who require financial assistance. Please contact us at info@parkinson.bc.ca or 1-800-668-3330 for more details.

SongShine for Parkinson's Webinar

Join us on Wednesday, April 1 as Sarona Mynhardt leads this fun, immersive, and holistic SongShine program, which engages participants in a music therapy-based singing intervention that can help to improve voice, respiratory control, and swallowing. It can also enhance quality of life for people that struggle with vocal atrophy due to aging, or neurological challenges like Parkinson's.

This program focuses on:

- Aligning the spine
- Articulation, breathing, and tongue exercises
- Singing and brain games

We welcome all individuals with Parkinson's to this webinar as well as their spouses and/or carepartners/caregivers, as they may benefit from learning more about the disease to assist in supporting their loved one.

Date: Wednesday, April 1

Time: 1:30pm – 2:30pm

Cost: Free

Registration: www.parkinson.bc.ca/songshine-webinar

Exercise Webinar Series: Move with Shelly

Join Parkinson Society British Columbia's own Education and Support Services Coordinator, and Neuro Physiotherapist, Shelly Yu, for a fun and energetic online Parkinson's exercise class, designed to challenge your strength, balance, and mobility. The class is shown with both standing and sitting options for varying levels of ability, and breaks will be given throughout. It will also incorporate components of dual-tasking to challenge cognitive processing. No

equipment is needed, with the exception of a chair to sit in, if desired. Movers will need about 2m of space to exercise in. All abilities are welcome. Let's get moving!

Date: Thursdays, April 2, 9, 16, 23, & 30
Time: 1:00pm – 2:00pm
Cost: Free
Registration: www.parkinson.bc.ca/move-with-shelly

Occupational Therapy Webinar Series: Independence using adaptive aids & technology

Join us for this three-part webinar series, led by Kathryn McKall, OT! She will be discussing the various adaptive equipment and technologies that can help people with Parkinson's disease maximize their quality of life and independence.

Kathryn is an occupational occupational therapist and Clinical Instructor at the University of British Columbia (UBC). She has been supporting people with neurological conditions since 2013, and currently works with the Parkinson's community at the UBC movement disorder clinic. She believes that "once you know one person with Parkinson's disease...you know one person with Parkinson's disease" – she believes in an individualized and accessible approach to assessment and intervention.

Date: Fridays, April 3, 15, & 24
Time: 1:30pm – 2:30pm
Cost: Free
Registration: <http://www.parkinson.bc.ca/ot-webinar-series>

Ask the Expert Webinar: Depression and Parkinson's

When most people think of Parkinson's disease, motor symptoms like tremors and slowness of movement are typically the first to come to mind. However, mental health changes can be a significant aspect of the disease as well, with at least half of all people with Parkinson's experiencing depression and/or anxiety.

Join us on May 12 as Dr. Fidel Vila-Rodriguez, Assistant Professor in the Department of Psychiatry at the UBC Faculty of Medicine, and the Director of the Non-Invasive Neurostimulation Therapies Laboratory and Schizophrenia Program, discusses the symptoms of depression and how to manage them. He will also go over current research on depression and Parkinson's, including an opportunity to participate in a clinical trial for treatment.

Date: Wednesday, May 12
Time: 11:00am – 11:00am
Cost: Free
Registration: www.parkinson.bc.ca/depression-webinar

UPCOMING FUNDRAISING EVENTS

Champions for Parkinson's

- Full Throttle: May 31 (read more: www.parkinson.bc.ca/fullthrottle)
- IMPACT Parkinson's: Ongoing event proceeds (see events: impactparkinsons.com)
- Donate a Car Canada: Ongoing (read more: bit.ly/2ORTuJn)
- Naturally Urban Pet Food Delivery Sales: Ongoing (read more: bit.ly/2MLasvX)

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? Become a Champion for Parkinson's and plan your own independent community fundraising event! Contact Caroline Wiggins at cwiggins@parkinson.bc.ca or 1-800-668-3330.

NEWS & ANNOUNCEMENTS

Online support groups

It is important to stay connected and support one another during this difficult time. Join one of Parkinson Society BC's online support groups, facilitated by our friendly and knowledgeable staff. See below for our support group offerings. Internet connection is required to participate.

NEW! COVID-19 Parkinson's Disease Online Support Group

In an effort to practice social distancing during the COVID-19 outbreak, many support groups have cancelled meetings until further notice. As a substitute, we have started a new weekly online support group for the Parkinson's community to help stay connected and support each other during this time. Please note this group will communicate via chat (typing).

Date: Weekly on Fridays
Time: 9:00am – 10:30am
Register: bit.ly/2QNvzhB

Young Onset Parkinson's Disease (YOPD) Online Support Group

This group is meant for individuals diagnosed with PD under the age of 60.

Date: 2nd Tuesday of each month
Time: 7:00pm – 8:30pm
Register: bit.ly/39qIXQC

Early to Mid-Stage Parkinson's Carepartner Online Support Group

This group is geared for individuals caring for someone with early to mid-stage PD. Whether you are a spouse, partner, adult child, or friend, we invite you to join our growing online community of support.

Date: 3rd Wednesday of each month
Time: 9:00am – 10:30am
Register: bit.ly/2JIMIQU

Advanced Parkinson's Carepartner Online Support Group

This group is designed for individuals caring for someone with advanced Parkinson's, which can be characterized by complex medical needs and/or changes in cognition that require help in almost all areas of daily life.

Date: 4th Thursday of each month
Time: 9:00am – 10:30am
Register: bit.ly/2wHjyUg

In-person support group cancellations

Due to the coronavirus outbreak, we have recommended that all support groups move their in-person meeting to either a teleconference or webinar format. Any modifications to meetings will be communicated on www.parkinson.bc.ca/coronavirus.

Retirement communities, recreation centres, and other public spaces may be especially vulnerable at this time. If you have concerns about your support group, reach out to your facilitator or get in contact with the management team at your meeting facility. Contact Jean Blake at jblake@parkinson.bc.ca for further guidance.

Step by Step suspended until further notice

Our 12-week walking program, Step by Step, runs each spring from April through June. Due to the COVID-19 outbreak, we have cancelled this year's program until further notice. For more information, please contact Shelly Yu at syu@parkinson.bc.ca.

Frequently asked questions about our webinars

To help you get the most out of your webinar or online support group experience, check out this new resource on our website, where we answer questions about how the platform we use and how to troubleshoot common issues: www.parkinson.bc.ca/webinarfaq.

Drug shortage updates

There is currently a shortage of instant-release formulations of SINEMET® (levodopa/carbidopa). An anticipated shortage end date was previously reported for July 2020. However, this date has now been pushed to March 2021. These formulations include SINEMET® IR 100 mg/25 mg and SINEMET® IR 250 mg/25 mg.

For more information and the most up-to-date news, please visit bit.ly/drug_shortage.

Continuing Education Scholarships

Parkinson Society British Columbia aims to provide opportunities for individuals who wish to pursue a career involving Parkinson's disease (PD) through our **Continuing Education Scholarship Program for Exercise Instructors & Healthcare Professionals**. This scholarship was established to assist people who have a passion to gain PD-specific training and bring these benefits to the BC PD community. Six scholarships up to \$1000.00 will be awarded in 2020. For more information: www.parkinson.bc.ca/continuing-education-scholarships.

Thank you & farewell to Stacey Dawes!

This month, we say goodbye to Stacey Dawes, Education & Support Services Manager. After 10 years with Parkinson Society British Columbia (PSBC), she is moving on to pursue new and exciting opportunities.

Stacey has been integral to PSBC's growth over the last decade, helping to expand our support group network and bring new life-changing programs, services, and education opportunities to the Parkinson's community. Stacey worked hard to establish relationships with healthcare

professionals and other Parkinson's networks to expand the resources offered to our members. Stacey's warm demeanor and friendly personality will be greatly missed within our office, but also out within the community. The Society would not be where it is today without Stacey's hard work and leadership, and we are grateful to have had her as part of our team! We wish her all the best in the next steps in her career.

Jean Blake, CEO, will be acting as our interim Education & Support Services Manager. For all matters relating to support groups, please contact Jean at jblake@parkinson.bc.ca.

APRIL IS PARKINSON'S AWARENESS MONTH!

Since 1969, Parkinson Society BC has served to empower the Parkinson's community by providing resources and services to enable self-management, self-reliance, and self-advocacy.

Every year, we dedicate the month of April to raising awareness of the unique experiences of people with Parkinson's, and the needs of our community. April Awareness Month is an opportunity to engage the public in expanding their understanding of Parkinson's, and the profound effects it has on the lives of over 13,000 British Columbians living with the disease.

This April, we want to spread the message that Parkinson's is more than a tremor. The disease can affect all aspects of one's life, and there is no cure.

Our 2020 campaign highlights:

- Personal journeys shared by people with Parkinson's, their families, and carepartners.
- The ambiguity of Parkinson's, and the uniqueness of each individual's symptoms, experiences, and disease progression.
- Advocacy issues affecting the Parkinson's community across British Columbia.

In recognition of Parkinson's Awareness Month, and World Parkinson's Day on April 11, we are encouraging individuals affected by the disease to share their experiences through our [#MoreThanATremor](#) campaign.

While most people have heard of Parkinson's disease, the breadth of symptoms experienced, and ripple effect the disease has on friends, family, and the healthcare system, are lesser understood. With approximately 13,000 people affected by the condition, Parkinson's is the second most common neurological disorder after Alzheimer's - yet it receives considerably less attention.

For more information on how to get involved, please visit www.parkinson.bc.ca/awareness.

Special Contribution

Express Yourself is a 10-part writing workshop for people with Parkinson's and carepartners, held in the winter of 2019. Led by Rebecca Gifford, this workshop guided new and experienced writers through writing and mindfulness exercises, as well as group meditation to help participants tap into their inner creativity and wisdom as a source of healing and strength.

Steven Ward submitted the poem below, written at Express Yourself.

Feeling courage despite trembling by Steven Ward

How do I breathe courage?
In the face of trembling?
How do I tremble without feeling fear,
fear of my disease's militant progress.
How do I hold my peace in a trembling body?
Seeing the clouds darken the setting sun,
the emboldened grey reaches deeper inside.
What must it have been like for my father as his legs began to stop working?
As he slowly slipped from crutches,
to wheelchair,
to bed.
We never talked about it.
Why would he?
How could he
with a young stupid teenager without much perspective.
What would you have said? I'm scared.
I hate this weakness.
I hate what it's doing to my life.
Way too out of character for this guy,
this guy who went up north in the fall hunting deer, moose and Elk on horseback with snow up
to his chest,
this guy who at 19 years of age
led work gangs building railroad bridges,
this guy whose Dad came home from the Great War
broken and silent.
No, it wouldn't have dawned on either him or me to talk about feelings. While he must have had
them, I never saw them,
never saw him frustrated, angry or depressed.
Just stoic, as he drew his withered legs up
into his van and drove to work each day
till a sudden, early end.
He was younger than I am now when he passed
but, if I am quiet,
I can feel his breath in me.

STAY SAFE, STAY HOME: Self-care during the COVID-19 outbreak

In response to the global outbreak of Coronavirus disease (COVID-19), Parkinson Society BC (PSBC) has been taking proactive measures to manage the potential for transmission. It is important that we all actively work to protect vulnerable populations, including older adults and those with underlying conditions. Although there is not enough data available to conclude whether or not Parkinson's disease makes you more susceptible to catching the coronavirus, or at risk of severe complications from COVID-19, it is important to follow the guidance of public health authorities during this time.

What is COVID-19, and why is it such a big deal?

COVID-19 is the name of the disease caused by a novel coronavirus discovered to be infecting people in the Hubei province of China in late 2019. This virus has since spread at an unprecedented rate, leading to its classification as a pandemic by the World Health Organization (WHO) this March.

The main symptoms associated with COVID-19 are fever, shortness of breath, cough, fatigue, weakness, and exhaustion. For about 80% of people, symptoms are classified as mild – this includes anything less than, or up to, mild pneumonia.

Because COVID-19 is so new, we know very little about it. We also don't have any treatment, cure, or vaccine for the virus at this time. While most cases are mild, about 20% of cases are more severe and require hospitalization. Current estimates put the death rate of the virus from about 1-4% of infected people. The severity of COVID-19, and its rapid rate of transmission, put a significant strain on the healthcare system in BC, and around the world.

Am I at high risk for complications from COVID-19?

This virus is too new for there to be any data on the specifics of COVID-19 and Parkinson's disease. However, there is a known increased risk for more severe outcomes for:

- older adults (60+)
- people with compromised immune systems
- people with pre-existing chronic conditions such as high blood pressure, heart disease, lung disease, cancer, or diabetes.

To date, there is no evidence to suggest that people with the above chronic conditions are more likely to contract this coronavirus, only that they are at an increased risk of developing severe illness if they catch it.

What precautions can I take?

The coronavirus spreads from person to person, through droplets released from the nose or mouth when an infected person coughs, sneezes, or exhales. You can contract the virus if you breathe in these droplets, or by touching infected objects or surfaces, then touching your mouth, nose, or eyes.

It is possible to contract the virus even from those who have little or no symptoms of COVID-19. This is why it is important to practice social distancing, and when necessary, self-isolate.

Follow these guidelines to stay safe during the outbreak:

- Wash your hands thoroughly with soap and water for at least 20 seconds. If you do not have access to soap and clean water, you can use hand sanitizer to clean your hands, as long as it contains at least 50% alcohol.
- Avoid touching your face. The virus can enter your body through your mucus membranes (in your eyes, mouth, and nose).
- Maintain at least 6 feet (2 metres) of distance from anyone you don't live with, at all times.
- Avoid leaving the house other than to get groceries and medication, for outdoor exercise, or fresh air. If you do need to leave the house, maintain a 6-foot distance from others, and avoid high-traffic areas.
- Avoid crowds as much as possible. Try to shop, visit the pharmacy, or run other errands at off-peak times whenever you can. You can also order deliveries, or seek support you're your network or volunteers.

I think I might have symptoms of COVID-19. What should I do?

BC's government and public health agencies recommend a self-assessment for COVID-19. The BC Ministry of Health developed an online self-assessment tool that will walk you through a series of questions and will provide guidance on next steps.

Not everyone with symptoms needs to be tested for COVID-19. Those who should be tested include people with respiratory symptoms (fever, cough, sore throat), who are:

- Hospitalized, or likely to be hospitalized
- Healthcare workers
- Residents of long-term care facilities
- Part of an investigation of a cluster or outbreak

People with no symptoms, or ones that can be self-managed at home, do not need to be tested.

People with Advanced Parkinson's or other high-risk conditions may fall under the category of "likely to be hospitalized." If you are experiencing symptoms, and worried about your condition, please self-isolate for 14 days and self-monitor your symptoms. Contact your doctor, or speak to a nurse at 8-1-1 if you notice any changes. In the event of an emergency, please call 9-1-1 immediately.

How can I manage my Parkinson's during the outbreak?

It is important you continue to receive your regular medical care for Parkinson's disease. Check with your healthcare team about future appointments. If you have symptoms of a respiratory illness (fever, cough, sore throat), please call ahead of any appointments so that your healthcare team can prepare to ensure everyone's safety.

If possible, keeping a two-week supply of your medication is encouraged, in case you may need to self-isolate. Contact your pharmacists to see if you can order more of your medication without physically going in. Your pharmacist may be able to deliver prescriptions to your home. If you are feeling unwell and require medications, please do not visit your pharmacy in-person; call instead.

Continue to self-manage as usual, as much as possible, while adapting to health authority guidelines. If you exercise outdoors, try at-home workouts and online classes – PSBC offers a few different options for Parkinson’s-specific home exercises. Practice social distancing by avoiding all non-essential interactions with anyone outside of your household. If you live alone, or with others who may be at higher risk for COVID-19 complications, try finding support from local home and community care services. Contact your health authority for more information.

How can I maintain my mental wellbeing while practicing social distancing and self-isolation?

Maintaining your mental health and wellbeing is largely about practicing balance. There are many ways to support a sense of balance in your life that involve structure, routine, and daily habits. Following the suggestions below can help you maintain and even improve your mental wellbeing:

- Eat regular, healthy meals whenever possible.
- Maintain a regular bedtime schedule and routine, even if your sleep is impaired.
- Start or maintain a regular exercise schedule.
- Spend time outdoors. Please take care to avoid public spaces and practice social distancing during this outbreak.
- Avoid unnecessary and constant news consumption.
- Get your information from reliable sources, like the ones listed at the bottom of this page.
- Maintain social interactions and relationships through phone calls, texts, and social media.
- Seek out and share positive and uplifting stories from your community.

Get support

Parkinson Society BC is committed to serving our community during the COVID-19 outbreak. Although many of our in-person education events have been cancelled or postponed, we will continue to provide support through online webinars and resources. To stay up-to-date on the latest resources and Parkinson’s-specific information about COVID-19, be sure to sign up for our mailing list by emailing us at info@parkinson.bc.ca.

Parkinson Society BC’s COVID-19 resources

Coronavirus precautions & updates on our services | www.parkinson.bc.ca/coronavirus

Frequently asked questions about COVID-19 | www.parkinson.bc.ca/covid19-faq

Maintaining your mental wellbeing | www.parkinson.bc.ca/mental-health-covid19

Online Parkinson’s resources | www.parkinson.bc.ca/resources-covid19

Online webinars, exercise classes, & support groups | www.parkinson.bc.ca/events

Additional resources

bc211: Safe Seniors, Strong Communities support service | bc211.ca | Call 2-1-1 for support

BC Centre for Disease Control | bit.ly/bccdc-covid19

BC COVID-19 Self-Assessment Tool | bc.thrive.health

COVID-19 in Canada | Canada.ca/coronavirus

COVID-19 Non-medical Hotline | Call 1-888-COVID19 or 1-888-268-4319

HealthLink BC | bit.ly/healthlinkbc-covid19 | Call 8-1-1 to speak to a nurse

World Health Organization | who.int/coronavirus