

SPECIAL NOTICE

In response to the global outbreak of COVID-19, Parkinson Society BC 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, please visit this PSBC web page:

www.parkinson.bc.ca/coronavirus. If you have any questions, please contact us at info@parkinson.bc.ca.

UPCOMING EVENTS

- **Mindful Moments** | Tuesdays, April 13 – June 1
Learn more & join waitlist: www.parkinson.bc.ca/mindful-moments
 - **Recreational Singing** | Wednesdays, April 14 – May 26
Learn more & join waitlist: www.parkinson.bc.ca/rec-singing
 - **SongShine with Joani** | Wednesdays, June 2 – July 14 | Wednesdays, July 21 – August 25
Learn more & register: www.parkinson.bc.ca/songshine-with-joani
 - **Dancing with Latin Rhythms** | Thursdays, June 3 – 24
Learn more & register: www.parkinson.bc.ca/latin-dance
 - **Balance & Falls Prevention Exercise Class** | Tuesdays, June 8 – July 27
Learn more & register: www.parkinson.bc.ca/balance-exercise
 - **Caregiving Series** | Wednesday, May 19 & 26
Learn more & register: www.parkinson.bc.ca/caregiving-series
 - **June Symposium Series** | Wednesday, June 9, Monday, June 14, & Friday, June 25
Learn more & register: www.parkinson.bc.ca/june-symposium
 - **Parkinson's Medication Q&A** | Friday, June 11
Learn more & register: www.parkinson.bc.ca/medication-webinar
 - **Debriefing the Caregiver Role** | Thursday, June 17
Learn more & register: www.parkinson.bc.ca/dtcr-webinar
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UPCOMING FUNDRAISING EVENTS

Champions for Parkinson's

- Full Throttle: Take a scenic ride along the Sea-to-Sky highway on Sunday, May 30 at the 5th Annual Full Throttle motorcycle and car ride! Funds raised from this event support Parkinson Society BC's programs, services, advocacy efforts, and research contributions. Learn more and register at 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? 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.

TIP JAR

The Tip Jar is where we share advice from Parkinson's community members. This month, we share advice on swallowing medications and avoiding dry mouth.

- One of our members in Powell River finds taking medications with a spoonful of yogurt or some soft, mashed banana helps ease pills down the throat when swallowing. Note that protein intake can affect medication absorption in some people with Parkinson's — if you have experienced this issue, there are many alternatives that may help, including applesauce and other fruit purees, or vegetable soups.
- A community member from Vancouver found that chewing gum helps reduce dry mouth, as well as tension in the jaw that can result from dystonia. They recommend Dentyne Ice Intense, which they found to remain soft, chewy, and flavourful for over an hour.

Do you have any tips or tricks that you would like to share with the PD 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.

NEWS & ANNOUNCEMENTS**World Parkinson Coalition Virtual: Advancing Science, Care, & Living with Parkinson's**

Registration is now open for the World Parkinson Coalition (WPC) Virtual Congress! Join the WPC Monday, May 17 through Friday, May 21 for talks on basic and clinical science in Parkinson's, treatment options, comprehensive care, and living well.

Registration to attend the WPC Virtual congress is \$25 USD. This includes access to all 20 pre-taped sessions, with three talks in each session, as well as all 20 live Q&A panels and both Wellness talk series on fitness and voice.

To learn more and register visit www.worldpdcoalition.org/page/WPCVirtual.

COVID-19 Vaccination

Throughout 2021, COVID-19 vaccines will be made available to all Canadians. The Government of Canada has announced a phased approach to immunization, and high-risk communities have begun receiving vaccinations to protect those who are most likely to develop complications from the virus. 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.

DISCUSSION TOPIC: Advocating for your healthcare**Discussion Questions**

1. How do you prepare for healthcare appointments?
2. What resources do you rely on to stay informed about Parkinson's disease?
3. How could you pursue better support from your healthcare team?

The key to ensuring you get the best possible care from your medical team is to be an active agent in your care plan. While advocating for yourself can feel daunting, it is an important part of helping healthcare professionals make informed decisions and tailor their approach to best suit your needs. Not all healthcare professionals know the extent to which Parkinson's disease (PD) affects everyone differently — each diagnosed patient they see will require an entirely unique care plan. By staying informed about PD and voicing your opinions, preferences, and concerns, you have the power to decide how your healthcare team can best serve you.

There are opportunities for self-advocacy at every healthcare appointment. Here are several ways you can start advocating for yourself at the doctor's office (NWPC Blog, 2018):

- Consider the reasons for your medical appointment and try not to deviate away from that topic until it has been adequately addressed, and your questions have been answered. Try making a checklist of talking points ahead of time so you don't forget anything.
- Before attending your appointment, spend time researching and educating yourself with information from reliable resources, so that you are aware of common symptoms, treatment plans, and medical jargon that healthcare professionals may use – Parkinson Society British Columbia has a wide range of helpsheets, booklets, and videos that cover topics including daily living, symptoms, treatments/medications, mental health, and legal considerations. View the full list of resources at www.parkinson.bc.ca/resources.
- You should never feel bullied, ignored, or like an annoyance – if this is the case, consider visiting a different healthcare professional who you can be comfortable and open with.
- If in doubt, seek a second opinion – staying informed about your condition and reaching out for a different perspective can help you avoid misdiagnosis or incorrect treatment.
- Reach out to friends and family for support – having people you trust advocating alongside you will give you strength and confidence in your healthcare journey.

Making the most of your medical appointment

Preparedness and organization go a long way in short medical appointments. In addition to the tips above, you can use the P.A.C.E. framework for effective patient communication. Developed by Dr. Donald Cegala, the framework is a way for patients to ensure they are contributing to a strong doctor-patient relationship. Individuals who have been trained to use the P.A.C.E. communication skills have been found to get more information from their doctors, and have a stronger partnership with their healthcare team.

P – Present detailed information about how you feel, including where symptoms are located, what they feel like, and how long they have been happening.

A – Ask any questions that come up. You can ask questions not only to solicit information from your healthcare professional, but also to make a request.

C – Check your understanding of the information that you have received by clarifying or summarizing what your physician said or asking them to repeat themselves.

E – Express any worries, concerns, or anxieties about your treatment plan. By being honest with your healthcare team, you can find the treatment option best suited to you.

Using telehealth for improved healthcare

Technology can also empower you to play a more active role in your healthcare. COVID-19 has introduced many new ways of accessing care – popular examples include phone or video chat appointments, or mobile phone applications like Babylon by Telus Health. Some individuals may have concerns over the safety, security, and effectiveness of telehealth. However, telehealth is required to adhere to the same high standards of security, privacy, and confidentiality as other forms of healthcare, and studies have shown that it can sometimes result in even more accurate diagnoses (Bloem et al., 2020).

If you are interested accessing telehealth, contact your healthcare team for more information on setting up a virtual appointment – they will also determine if telehealth is suited to your needs. Before your appointment ensure your smartphone, tablet, or laptop is fully charged or connected to power and has a strong internet connection. You may also want to consider using headphones with a microphone for better audio quality. During the visit, your doctor will confirm identification, and then ask you to provide many of the same details and information as you would during an in-person appointment.

These new platforms allow individuals to quickly and easily connect with doctors, nurses, and other healthcare professionals without having to leave home. For people with Parkinson's, these methods can be a particularly effective and empowering way to receive necessary care.

Better care for the whole community

While treatment for Parkinson's disease can be complex, it is one of the most treatable neurological conditions. With expert and appropriate treatment and therapies, disease progression can be managed, decreasing risk of falls, hospitalizations and referrals to long term care. Well managed patients can live independently for many years.

Medical therapy for Parkinson disease is complex, but must be complemented by physical training and prevention of other complications like choking, social isolation and withdrawal due to communication impairment (softened speech) and caregiver burden and life transitions as patients' needs increase.

Research shows that people who receive skilled care are at a lower risk of complications and have better quality of life. Parkinson's disease patients have a fracture risk approximately twice that of age-matched controls due to their risk of falls, lower bone mass, and frailty; hip fracture rates are higher than in age-matched controls and may occur in up to 27% of patients with PD within 10 years of diagnosis.

Canadian Guidelines for treatment of Parkinson's Disease emphasize the importance of multidisciplinary care for Parkinson's disease and recommend all patients have access to allied health personnel including physical therapy, speech language pathology and social work.

Parkinson Society BC believes that all people living with Parkinson's deserve access to comprehensive, team-based care. Unfortunately, throughout the province, there are very few experts accessible to the PD community — those who are available often have long waitlists. Many people with PD are forced to choose between delaying their treatment in order to see these experts, or receiving it from healthcare professionals in emergency rooms, hospitals, general practices, or care homes, who lack knowledge of PD and best practices in disease management.

Access to Comprehensive, Team-based Care

Parkinson Society BC is working to improve this access and has invested in improving team-based care at the Movement Disorder Clinics in Kelowna, Victoria and is also currently working

to partner with the UBC Clinic in Vancouver. The Society is funding allied healthcare positions at these clinics for a period of five years with the clinics taking over the funding in the sixth year.

Patients being treated at the Kelowna clinic now have access to a physiotherapist, speech pathologist and a social worker. In Victoria, a speech pathologist is now available for your care and at UBC, Vancouver, an occupational therapist and speech pathologist will soon be available. These positions are funded through Parkinson Society BC's donor program and over the five years and the three clinics represent \$1.5 million dollars in donations. Your support is vital to continuing these partnerships.

The Society's future plans include working with Fraser Health, Abbotsford East, and Northern Health to bring visiting clinics to these regions.

Your support in fund raising through events like SuperWalk or an individual gift will help us to continue these initiatives. We are dedicated to improving Parkinson's care across BC. If you are interested in supporting the PD community as an advocacy volunteer, contact CEO, Jean Blake, at jblake@parkinson.bc.ca. Visit www.parkinson.bc.ca/advocacy to learn more.

Additional Resources

Your Healthcare Team | Helpsheet | <http://bit.ly/pdhealthcareteam>

Preparing for a Medical Appointment | Checklist | <http://bit.ly/pdappointmentprep>

Comprehensive Care Plan | Checklist | <http://bit.ly/pdsymptomchecklist>

Raboud Oral Motor Inventory for Parkinson's | Checklist | <http://bit.ly/raboudsinventory>

Aware in Care | Medical Kit | www.parkinson.bc.ca/awareincare

Sources

Bloem, Bastiaan R. et al. (2020). *The Coronavirus Disease 2019 Crisis as Catalyst for Telemedicine for Chronic Neurological Disorders*. JAMA Neurol. Retrieved from: <https://bit.ly/32KeGeP>.

NWPC. (March, 2018). *How to Advocate for Yourself at the Doctor*. Northwest Primary Care. Retrieved from <https://www.nwpc.com/how-to-advocate-for-yourself-at-the-doctor>.