

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

- **Thawing Out: Exercises for Freezing** | Thursdays, October 15, 22, 29, & November 5
Learn more & register: www.parkinson.bc.ca/thawing-out-series
 - **Exploring the Role of Cannabis in Parkinson's Treatment** | Tuesday, October 20
Learn more & register: www.parkinson.bc.ca/cannabis-webinar
 - **Ask the Expert Webinar: Dementia in Parkinson's** | Wednesday, October 28
Learn more & register: www.parkinson.bc.ca/dementia-webinar
 - **Ask the Expert Webinar: Parkinson's Medication Q&A** | Friday, October 30
Learn more & register: www.parkinson.bc.ca/medication-qa
 - **Gut Health Series** | Mondays, November 9 & 16
Learn more & register: www.parkinson.bc.ca/gut-health-series
 - **Dance the Holidays: Nutcracker Repertoire** | Thursdays, November 12, 19, 26, & December 3
Learn more & register: www.parkinson.bc.ca/dance-nutcracker
 - **November Symposium Series** | November 18, 25, & 30
Learn more & register: www.parkinson.bc.ca/november-symposium
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***Moving Forward, Together* Provincial Conference**

Our provincial conference is moving online! Featuring presentations from prominent Parkinson's specialists and researchers across the country, this year's *Moving Forward, Together* will be a fully virtual experience. The half-day event will offer three plenary talks, with opportunities for participants to ask their questions of our expert speakers. Just like our in-person event, we will also offer guided exercise breaks, and host a virtual exhibition hall.

Topics covered include:

- The Evolution of Defining and Diagnosing Parkinson's Disease | *Dr. Anthony Lang*
- The Research-Based Benefits of Exercise for Parkinson's | *Dr. Matthew Sacheli*
- Understanding the Development of Parkinson's Disease and Related Therapies | *Dr. Jon Stoessl*

Date: Saturday, October 17
 Time: 9:00am – 12:30pm
 Fees: Member: \$30 | Non-member: \$40
 Register: www.parkinson.bc.ca/movingforward

UPCOMING FUNDRAISING EVENTS

Champions for Parkinson's

- 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

Save the Date: 2019 Annual General Meeting

We welcome all members of Parkinson Society British Columbia to join us for our 2019 Annual General Meeting (AGM) this fall. In light of the COVID-19 outbreak, this year's AGM will be hosted virtually. Stay tuned to our website at www.parkinson.bc.ca for more details. Registration will be available soon.

Date: Saturday, November 21

Time: 9:30am – 11:30am

Cost: Free for members. Non-members interested in attending must sign up to be a member of PSBC, and pay the \$25 annual membership fee.

Above and Beyond Volunteer Recognition Awards

Parkinson Society BC recognizes people with Parkinson's and their caregivers who have gone above and beyond with others in their communities and who demonstrate a passion to celebrate each day with joy, compassion, and understanding.

These individuals are true examples that people affected by Parkinson's can live rich, full lives. They make an effort to open up new opportunities and foster relationships they had never imagined possible before their diagnosis.

At our upcoming AGM, we will recognize some of the contributions to the community based on nominations received. Please nominate someone from your community who embraces the "Above and Beyond" philosophy in their life. Nominations must be received by Wednesday, October 21. Nominate someone online at www.parkinson.bc.ca/aboveandbeyond.

Parkinson SuperWalk

Thank you to everyone for your enthusiastic participation in, and generous donations to, the 30th annual Parkinson SuperWalk. This year, your incredible support has helped to raise over \$233,000 and counting. These funds will allow the Society to expand its reach, providing advocacy, programming, support services, and contributions to research for the 13,000 British Columbians living with Parkinson's, and their carepartners and families. Stay tuned to our website, where we'll be announcing our top fundraisers and teams!

If you couldn't join us this year, it's not too late to help us make a difference. Donations for this year's SuperWalk will be accepted through December 31st, 2020!

DISCUSSION TOPIC: Parkinson's in the Family**Discussion Questions**

1. How has Parkinson's affected your family dynamic and relationships?
2. What are some ways your family finds strength?
3. What are some activities you and your family enjoy doing together?

For many families, Thanksgiving is an important time to get together and strengthen emotional bonds with loved ones. However, it can also be a stressful time when you're living with Parkinson's disease (PD) or are a carepartner. As PD progresses, it can have an effect on family dynamics, and impact the ways people with the disease are able to spend time with others year after year. Parkinson's can influence how you eat, the activities you can participate in, and how you are able to communicate with others. It is important to be as open and honest with your family and friends as possible, so you may work together to make adjustments to ensure that your holiday plans are inclusive, accessible, and fun for everyone.

Note: Keep COVID-19 restrictions and safety guidelines in mind when planning your family gatherings this fall and winter. It is best to avoid seeing others in person if anyone in your party may have been exposed to coronavirus. If you will be gathering with loved ones, keep your circle small (aim for a maximum of 6 people), avoid long travel, keep outdoors when possible, and consider self-isolating before and after the holiday. Read BC's COVID-19 guidelines here: <https://bit.ly/covidinbc>.

Adjusting to a New Dynamic

Accepting a Parkinson's diagnosis can often take time. Just as people with PD may need time to process and adjust to changes that the disease introduces, their loved ones also need time to adapt to a future that may look different from what they had planned. There can be a sense of ongoing grief or loss associated with Parkinson's as symptoms progress and affect daily life, and there must be a focus on leaving time to process these feelings. While the progressive nature of the disease can be intimidating, one of the best ways to cope is by learning about the disease, treatments, and resources available, and leaning on a solid network of friends, family, and healthcare professionals.

Another change that may alter family dynamics is when loved ones transition into caring roles, which can be both rewarding and challenging. It is important to recognize that care needs may shift from day to day, even hour to hour. People with PD should be open and specific with their carepartners about what kinds of support they need, while respecting their capacity for care.

Remaining as independent as possible can also help with maintaining healthy boundaries in relationships (Parkinson's Victoria, 2020). Alone time may help create space to prioritize self-care and mental health. Taking opportunities to reverse the caring role can be another way to show love and support to those around you (Parkinson's Victoria, 2020). This may look like offering to make a cup of tea for your carepartner, or watching the children while your spouse takes some time out. Simple ways of showing care will facilitate healthy, reciprocal family relationships. Finding new activities you can all do together is also a great way to strengthen relationships.

Communication is Key

While humans are naturally attracted to connect with one another, it can often be challenging to communicate our feelings in a way that others understand, especially when confronted by a complex disease like Parkinson's. While difficult, talking through hard topics in a productive way with family is crucial to good health and well-being, as family is often where our strongest emotional memories are formed (Segal, 2019).

First of all, it is important to ensure you are truly listening to each other. Absorb what others express and make sure you are not just waiting your turn to speak. Secondly, exercise emotional choice – express anger in measured tones instead of with a temper, avoid using absolutes like ‘always’ and ‘never’, and use ‘I’ instead of ‘you’ to express concerns (Schwartz, 2006). Thirdly, try to be aware of each person’s unique needs and be generous in expressing love (Schwartz, 2006). Simple reassurances like loving words or gestures can mean a lot to someone and nurture emotional trust within the family. If communication is becoming more challenging and emotional needs are not being met you may want to consider seeking professional support through counselling.

Alongside emotional communication, Parkinson’s may affect your physical ability to communicate. To strengthen your voice, speech, and communication abilities, try the following self-help strategies:

- Get your listener’s attention before speaking, and maintain eye contact with them.
- Avoid speaking in the presence of distracting background noise.
- Swallow before speaking to clear any pooled saliva.
- Speak slower and louder than you are used to, ensuring every word is clear.
- Clarify topics with a phrase such as “I would like to talk about...”
- Try to plan important conversations for when you are feeling your best (medication “on” time).

Speech-language pathologists can provide more strategies to improve communication problems for people with PD. Evidence-based programs like the [Lee Silverman Voice Treatment \(LSVT® LOUD\)](#) can also be effective speech treatment.

Children and Parkinson’s

Children’s reactions to learning about a PD diagnosis may vary; some may become sad and need time to process these feelings, while others may act as though nothing has changed. Trying to shield children from a PD diagnosis can do more harm than good, so be open and honest. You may wish to explain it to them as something that will present challenges, but also something from which one can learn and grow. For younger children, explain the diagnosis in simple terms, and be prepared to answer basic questions around fatality and contagiousness. For teens, consider using the internet together to identify reliable sources they can turn to for information. Maintaining as much consistency as possible around parenting, discipline, and boundaries is beneficial for facilitating a sense of comfort and routine for children. Activities like regular family meetings, fun outings, and getting involved in the PD community together can help unite your family and foster supportive relationships. Be sure to let children know that they can ask any questions or concerns that may arise for them.

Additional Resources

Caring in the Family | <http://bit.ly/pdffamilycare>
Carepartner Grieving and Loss | <http://bit.ly/carepartnergrieving>
Voice and Communication Problems in PD | <http://bit.ly/pdvoiceproblems>
A Family Affair: Talking to Children about PD | <http://bit.ly/pdguidekids>
Information for Teens about PD | <http://bit.ly/pdguideteens>
Counselling | www.parkinson.bc.ca/counselling
Support Groups | www.parkinson.bc.ca/support-groups

Sources

Parkinson’s Foundation (2020). *Talking to Children About Parkinson’s*. <https://bit.ly/2Gev2mB>
Parkinson’s Victoria (2020). *Relationships and Family Life*. <https://bit.ly/2SmVqO9>
Schwartz, A. (2006). *Stuffing It: The Culture of Not Speaking*. <https://bit.ly/3jdF85X>
Segal, J. (2019). *Improving Family Relationships with Emotional Intelligence*. <https://bit.ly/2S6wuKq>