



ANNIVERSARY

Parkinson Society British Columbia

CELEBRATING 50 YEARS OF SERVICE IN 2019!

Since 1969, Parkinson Society British Columbia has been proud to empower people with Parkinson's across the province, through education, support services, advocacy, and fundraising. This year, join us as we celebrate the strength of our community, and the many milestones we have reached together. We hope to extend our reach wider than ever before – within the Parkinson's community and beyond.

Throughout the year, we will be sharing inspirational stories from the people with Parkinson's, carepartners, and advocates in our community. If you have a story to share about your life with Parkinson's, we would love to hear it! For more information, email us at info@parkinson.bc.ca, or call 1-800-668-3330.

UPCOMING EVENTS

Parkinson Society British Columbia (PSBC) 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 email info@parkinson.bc.ca or call 1-800-668-3330 for more details.

COMMUNICATION AND SWALLOW WORKSHOP, VANCOUVER

This interactive and participatory workshop, led by Registered Speech Language Pathologist Sherri Zelazny, will focus on the communication and swallowing challenges faced by people with Parkinson's. It is open to those already experiencing communication and swallowing challenges, as well as those who wish to be proactive in their treatment.

Date: Saturday, February 9
 Time: 10:00am – 2:30pm (registration opens at 9:30am)
 Location: Italian Cultural Centre Vancouver
 3075 Slocan Street ([map](#))
 Cost: Member \$25.00 | Members (Pair) \$40.00
 Non-member \$35.00 | Non-members (Pair) \$60.00
 Registration: www.parkinson.bc.ca/vancouver-communication-workshop

ASK THE EXPERT WEBINAR: SELF-MANAGEMENT AS SELF-CARE

Self-management refers to the tasks that an individual must undertake to live well with one or more chronic health conditions. These tasks include gaining confidence to deal with medical management, role management, and emotional management. John A. Murphy, Coordinator of the Vancouver Coastal Region of Self-Management BC, will give us an introduction to self-management, and how learning these skills can improve your quality of life with Parkinson's – today, and in the future.

Date: Tuesday, February 19
 Time: 10:00am – 11:00am
 Location: Via webinar. *Instructions on how to access the presentation will be sent out 24 hours before the event's start time.*
 Capacity: 200
 Cost: Free
 Registration: www.parkinson.bc.ca/self-management-webinar

UPCOMING EVENTS

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REGIONAL CONFERENCE, VICTORIA

Parkinson's disease is a unique and complex condition. To assist in expanding your knowledge of the disease, on March 2nd, Parkinson Society British Columbia will host an afternoon of learning in Victoria.

Our regional conferences are immersive and interactive opportunities for people affected by the disease to learn from leading experts while connecting with the Parkinson's community. The conference does not include a meal, however light refreshments will be provided.

Topics covered at this conference will include:

- **Frequently Asked Questions:** Dr. Tara Rastin, *Movement Disorder Specialist from the Pacific Parkinson's Research Centre*
- **Speech and Technology:** Susan Edwards, *Registered Speech-Language Pathologist*
- **Research Updates at the Pacific Parkinson's Research Centre:** Emma Kiss, *Research Assistant*, and Michelle Doo, *Research Coordinator*

Date: Saturday, March 2
Time: 1:00pm – 4:15pm (registration opens at 12:30pm)
Location: Sandman Hotel
2852 Douglas Street ([map](#))
Cost: PSBC Member \$15.00 | PSBC Members (Pair) \$25.00
Non-member \$25.00 | Non-members (Pair) \$45.00
Registration: www.parkinson.bc.ca/victoria-conference

For a listing of all upcoming education events, visit our [education events calendar](#).

UPCOMING FUNDRAISING EVENTS

Champions FOR PARKINSON'S

- Chocolate & Beer Tasting: Sunday, March 10 [[read more](#)]
- Donate a Car Canada: Ongoing [[read more](#)]
- Naturally Urban Pet Food Delivery Sales: Ongoing [[read more](#)]
- Tea Parky: In this ongoing fundraiser, 35% of proceeds from every sale on TeaParky.com will go to Parkinson Society BC. *Special: Use promo code PSBC at checkout for 10% off your purchase.*

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! Please contact Mirela Prime at mprime@parkinson.bc.ca or 1-800-668-3330.

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 with us at info@parkinson.bc.ca or 1-800-668-3330.

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DEEP BRAIN STIMULATION: GOOD NEWS FOR BC PATIENTS!

Effective April 1, 2019, Dr. Christopher Honey, UBC neurosurgeon, will be increasing his operating time to accommodate 70 Deep Brain Stimulation surgeries annually, instead of the current 35. We appreciate the work done by the Vancouver Coastal Health Authority and the Ministry of Health to make this happen. We are hopeful that this increase in operating room time will allow some patients, who have been waiting for up to three years, to access this life-changing surgery.

To learn more about this announcement, visit www.parkinson.bc.ca/dbs-january-update.

WARM WELCOME! TRICIA WALLACE

Clinical Counselor (available Tuesdays only)

Parkinson Society BC is excited to welcome our new part-time Clinical Counselor, Tricia Wallace!

Tricia has practiced as a registered nurse since 1988 in hospital and community settings, attaining a Bachelor of Science in Nursing and a Master of Nursing from the University of Victoria, BC. Currently, she is completing a Master of Arts in Counselling Psychology at Yorkville University. Tricia has extensive experience working with adults of all ages in the field of mental health, including case management for those 55 and older who live with co-occurring disorders, and work as a clinical educator on a neuropsychiatric inpatient ward. As a result, Tricia has knowledge of medications and neurodegenerative disease processes that may inform work in counselling sessions. She also recognizes the importance of a strength-based, holistic approach to Parkinson's disease that includes emotional support and skill building for individuals and their families.

To learn more about Parkinson Society British Columbia's counselling services, visit <https://www.parkinson.bc.ca/counselling> or email info@parkinson.bc.ca.

NEW! SURREY SUPPORT GROUP

This group is intended for anyone affected by Parkinson's disease. Carepartners, friends, and family members are welcome.

Date: 2nd Monday of each month
Time: 6:00pm – 7:00pm
Location: Amenida Seniors' Community - Downstairs Activity Room
13855 68th Ave, Surrey ([map](#))

SAVE THE DATE: WORLD PARKINSON CONGRESS 2019, KYOTO

The 5th World Parkinson Congress (WPC) will be held in Kyoto, Japan from June 4th – 7th, 2019. Are you interested in attending? Registration is open now. Early registrants benefit from a discount until February 27, 2019. Full information on registration categories is available at www.wpc2019.org/page/RegFees.

STEP BY STEP

Starting Tuesday, April 11, Parkinson Society BC is bringing back the Step by Step program for a fourth consecutive year! Step by Step is a 12-week walking program aimed at incrementally improving the number of average daily steps an individual takes. The first week will determine each walker's baseline, and then each week, they will be encouraged to increase their steps based on a personal goal. While participants are encouraged to walk and track their own steps, a community group leader will organize a weekly walk allowing walkers to meet, socialize, and support one another.

Interested in becoming a Step by Step leader in your community? Contact Caroline Wiggins at cwiggins@parkinson.bc.ca, or call 1-800-668-3330 to learn more.

Note: Any listings above should not be considered an endorsement of the third-party event(s). As such, the Society cannot be held responsible or liable for any loss or damage suffered as a result of participation.

DISCUSSION QUESTIONS:

1. What does intimacy mean to you?
2. How can you build a stronger connection with your loved ones/friends?
3. Do you know what sexual health resources are available to you in your community, or online?

Intimacy is a broad term, and may mean different things to each person. It is often thought of in a sexual context, but it involves much more than just sexual intercourse. Intimacy means having a close, trusting connection with someone, including loved ones and friends. It can be challenging to build intimacy when dealing with motor symptoms and mood changes that may make someone with Parkinson's disease (PD) want to shut down. Enhancing your connection with someone, therefore, begins with addressing your own isolation, if you experience it.

The most important tool in intimacy is good communication. Prioritizing effective and open communication can increase a sense of understanding in your relationships, which can make them more fulfilling. It is important to first become aware of what your own needs are in your relationships, and to communicate those with your loved one or friend. For example, if you would like to spend more time together, or you'd like to focus on something other than PD, it is important that you ask for that.

Another way to build intimate connection is to get out of your usual routine. Doing something new and exciting with your loved one or friend can reignite your relationship. Consider going to a new restaurant, or travelling to a new destination. It's important to note that changes to your routine do not need to be spontaneous, and can be planned out in advance to accommodate your needs.

SEXUAL CHALLENGES IN PARKINSON'S

In Parkinson's, sexual dysfunction can arise from the changes in dopamine levels and the autonomic nervous system (the system that controls our blood pressure, heart rate, erections, swelling of the clitoris, etc.). PD symptoms also cause difficulty with fine movements, coordination, and moving freely in bed. Couples may need to be willing to experiment to find the most comfortable and satisfying positions during sexual activities.

In addition to difficulties with movement, people with Parkinson's and their sexual partners may experience the following:

- Symptoms such as tremor, rigidity, loss of facial expression, and speech impairment reduce body language in people with PD. Partners can mistakenly think they are being ignored or not loved.
- Parkinson's can affect one's self-image. The person with PD may feel less sexually attractive, or their partner may find it psychologically difficult to move beyond PD symptoms to see their partner as a sexual being.
- The slowness of Parkinson's can manifest as loss of initiative and greater passivity. This can impose a more active role on their partner. Sexual role changes require healthy dialogue and a willingness to adapt.
- Parkinson's disease can cause fatigue and energy fluctuations. It may be necessary to change your routine, or be flexible in terms of when intimacy may occur. Scheduling time together in your calendar can help with this.
- Depression can create or aggravate sexual dysfunction. Anti-depressant medications may be required. Mood-regulating drugs may also need to be adjusted, as some can impair sexual desire or delay orgasm.
- Some PD medications can cause hyper-sexuality, as well as other compulsive behaviours, such as excessive shopping or gambling. These behaviours may be quite foreign to the person, and extremely distressing and embarrassing. Drug adjustments may be required in such cases. It is very important to notify your physician about these behaviors if they should occur.
- In men, erectile dysfunction and delayed or premature ejaculation are common. Sometimes, low sexual desire is a problem. Women with or without PD may, at times, experience a decrease in sexual desire, difficulty with arousal and orgasm, and painful intercourse. Interestingly, it is the women whose male partners have PD that report very distressing sexual lives – far more so than women who have PD themselves. For this reason, it is important for women whose partners have PD to communicate any sexual challenges they are experiencing with their partner, and, if a solution can't be negotiated, to speak with their physician.

Helping to care for a loved one with PD can potentially change sexual relationships. Often, there is a tendency for sexuality to be focused on the frequency and quality of intercourse as a benchmark of their relationship and sexual health; however, sexuality extends far beyond intercourse. Chronic illnesses like Parkinson's can challenge couples to expand their perception of sexuality and intimacy to include gentle kisses, hugging, loving eye contact, or listening deeply to what is said as part of caring for one another. Genital sensations can be enjoyed, with or without orgasms, and intercourse is not necessary.

ADDITIONAL RESOURCES

Maintaining Sexual Intimacy with Parkinson's | Webinar | youtu.be/004RgmVyelo

Intimacy and Sexual Health | Video | vimeo.com/116124115

Sexual Intimacy and Parkinson's | Helpsheet | bit.ly/pdintimacy

OPTIONS FOR PROFESSIONAL CONSULTATIONS

BC Centre for Sexual Medicine
(physician referral required)
500 – 575 West 8th Avenue, Vancouver, BC
604-875-8282 | bit.ly/2Hn3KdU

GF Strong Sexual Health Rehab Centre
(physician referral required)
4255 Laurel Street, Vancouver, BC
604-737-6291 | bit.ly/2HmtMOK

Victoria psychiatrist Dr. Gail Knudson
(physician referral required)
201 – 1770 Fort Street, Victoria, BC
250-592-6183

Victoria sexual medicine physician Dr. Marjon Blouw
(physician referral required)
101 – 1964 Fort Street, Victoria, BC
250-721-9494

BC Association of Clinical Counsellors
(services may not be covered by Pharmacare)
www.bc-counsellors.org

BC Psychological Association
1-800-730-0522 | www.psychologists.bc.ca

Options for Sexual Health
1-800-SEX-SENSE | www.optionsforsexualhealth.org

SOURCES

National Parkinson Foundation (1998). Impotence in Parkinson's Disease. Parkinson Report, XIX, (3).

Parkinson's UK (2014). Intimate Relationships and Parkinson's. Retrieved from https://www.parkinsons.org.uk/sites/default/files/publications/download/english/b034_intimaterelationshipsandparkinsons.pdf