

A MONTHLY NEWSLETTER BY PARKINSON SOCIETY BC FEBRUARY 2020 ISSUE

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.

PARKINSON'S CAREPARTNER WEBINAR SERIES

Parkinson Society BC recognizes that Parkinson's affects not only the person with the diagnosis, but family and friends as well. This webinar series aims to support carepartners through information and tools to help cope with the stresses of caregiving.

We welcome all individuals in a caring role to this webinar series, and we encourage participants to bring their questions to each session as there will be time set aside for Q&A and discussion.

Please note that separate registration is required for each session.

Important: If you will be watching a presentation with a partner or group, only one registration is required. Instructions on how to access the presentation will be sent with your registration confirmation email, and a reminder sent approximately 24 hours before the event's start time.

Date: Wednesdays, March 4, 11, & 25

Time: 10:00am - 11:00am

Cost: Free

Registration: <u>www.parkinson.bc.ca/carepartner-series</u>

Personal Support and Healthcare Resources for Carepartners Wednesday, March 4

Isobel Mackenzie has over 20 years' experience working with seniors in home care, licensed care, community services, and volunteer services.

In this session, she joins Parkinson Society BC (PSBC) to provide an overview of the services offered by the Office of the Seniors Advocate. She will also discuss personal support and healthcare resources available to seniors in British Columbia, and information on how to access them.

Mindfulness for Carepartners Wednesday, March 11

"You can't stop the waves, but you can learn to surf." - Jon Kabat-Zinn

Join PSBC's own Tricia Wallace, clinical counsellor, to discuss the benefits of mindfulness for carepartners and caregivers. This webinar focuses on mindfulness as a coping tool for life, to navigate the many stressors brought on by the caring role, including isolation, lack of leisure time, and the progression of your loved one's disease. Tricia will introduce mindful practices and resources, as well as quide a short group meditation.

Ambiguous Loss and Anticipatory Grief Wednesday, March 25

Ambiguous loss is a type of loss that is unclear or without closure, and anticipatory grief is the feeling that one may experience when expecting a loss or change. As Parkinson's progresses, many carepartners and caregivers find themselves experiencing these kinds of loss and grief, and feeling isolated as a result.

Trevor Josephson, Clinical Manager at Peace Arch Hospice Society, joins PSBC for the first time to discuss ambiguous loss, anticipatory grief, and methods for coping.

REGIONAL CONFERENCE | VICTORIA

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Parkinson's disease is a unique and complex condition. To assist in expanding your knowledge of the disease, on March 7, Parkinson Society BC 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.

Topics covered at this conference include:

- Parkinson's Symptoms & Prognosis | Dr. Keiran Tuck, Movement Disorder Specialist at Royal Jubilee Hospital, Victoria
- Medication Management | Amy Tran, Pharmacist
- Independence Using Adaptive Aids & Technology | Kathryn McKall, Occupational Therapist at the Pacific Parkinson's Research Centre, UBC

Date: Saturday, March 7

Time: 1:00pm - 4:30pm (check-in begins at 12:30pm)

Location: Sandman Hotel

2852 Douglas St, Victoria [map]

Cost: Member: \$15 | Member Couple/Pair \$25

Non-member: \$25 | Non-member Couple/Pair \$45

Registration: <u>www.parkinson.bc.ca/victoria-conference</u>

COMMUNICATION & SWALLOW WORKSHOP | ABBOTSFORD

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.

Abbotsford: Saturday, March 14 Time: 10:00am - 2:30pm

Location: Quality Hotel & Conference Centre

Pinnacle 1

36035 Parallel Rd, Abbotsford [map]

Cost: Members: \$25 | Pair \$40

Non-members: \$35 | Pair \$60

Registration: www.parkinson.bc.ca/abbotsford-cs

FOR A LIST OF ALL UPCOMING EDUCATION EVENTS, VISIT <u>WWW.PARKINSON.BC.CA/EVENTS</u>

FUNDRAISING EVENTS



- Chocolate & Beer Tasting: March 8 [buy tickets]
- Donate a Car Canada: Ongoing [learn more]
- Naturally Urban Pet Food Delivery Sales: Ongoing [learn more]

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 Caroline Wiggins at cwiggins@parkinson.bc.ca or 1-800-668-3330.

NEWS & ANNOUNCEMENTS

STEP BY STEP RETURNS THIS APRIL!

Starting Saturday, April 11, Parkinson Society British Columbia is bringing back the Step by Step program for the sixth 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 Shelly Yu, Education and Support Services Coordinator, at syu@parkinson.bc.ca, or call 1-800-668-3330.

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.

The program is open to any professional interested in working with this population. Scholarships will be awarded to applicants who demonstrate a strong commitment to supporting those with PD through long-term community engagement and programming. Special consideration will be given to applicants living in communities with limited resources for people with Parkinson's.

Six scholarships up to \$1000.00 will be awarded in 2020.

For more information: www.parkinson.bc.ca/continuing-education-scholarships

WE'RE LOOKING FOR A SUPPORT GROUP FACILITATOR IN CRANBROOK!

Parkinson Society British Columbia is actively recruiting a volunteer Support Group Facilitator to assist in maintaining and strengthening the Parkinson's community in Cranbrook.

The responsibilities of the Support Group Facilitator include:

- Working to create an environment that is safe and respectful, and where participants feel comfortable sharing their experiences, insights, and knowledge with others.
- Assisting with the delivery of information, education, and resources for people with Parkinson's and their carepartners/families.
- Leading support group meetings once a month, for a couple of hours, from September to June.

Facilitators are supported by Parkinson Society British Columbia through access to information and resources, teleconference calls, bi-annual one-on-one follow-ups, advocacy/awareness campaigns, and educational opportunities.

For more information about this position, and to apply, please contact Stacey Dawes, Education and Support Services Manager, at sdawes@parkinson.bc.ca or 1-800-668-3330.

MOVAPO (APOMORPHINE) NOW AVAILABLE UNDER THE LIMITED DRUG COVERAGE PROGRAM

As of November 26, 2019, Movapo has been made available under BC PharmaCare's Limited Drug Coverage Program. For more information, visit: bit.ly/Movapo-Announcement.

UPDATE! WEST KELOWNA SUPPORT GROUP DATE AND TIME

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

Date: 2nd Monday of each month Time: 10:00am - 11:30am

Location: The Heritage Retirement Residence | Theatre Room

3630 Brown Rd, West Kelowna [map]

NEW UBC STUDY FINDS LINK BETWEEN PARKINSON'S AND AIR POLLUTION

Researchers from the University of British Columbia (UBC) faculty of medicine found that adults living less than 50 metres away from a major road, or less than 150 metres from a highway have a higher risk of developing Parkinson's, dementia, Alzheimer's, and Multiple Sclerosis.

Learn more by reading the UBC news story at bit.lv/ubc12320, or read the full study at rdcu.be/b0HX7.

DISCUSSION: INTIMACY & SEXUAL HEALTH

DISCUSSION QUESTIONS:

- 1. What does intimacy mean to you, apart from sexual gratification?
- 2. How do you feel about being intimate as a person with Parkinson's, or a carepartner to someone with Parkinson's?
- 3. Where do you go to get resources and support for sexual health?

Roughly half of all people with Parkinson's disease (PD) will experience challenges with intimacy and sexual function. Conversations about intimacy and sexual activity can be difficult, but it is important to remember that you are not alone in any of the symptoms you may encounter.

INTIMACY

Sex and intimacy are separate and complementary elements of a relationship. Intimacy is an emotional and cognitive experience that can enhance physical elements of sex, strengthening a couples' bond. It can also stand on its own as an important and enduring foundation for loving connection.

Intimacy involves safety, sharing, tenderness, validation, compassion, and acceptance communicated not only with words, but through touching, gestures, and hugs. Intimate bonds grow with connection through shared activities and honest but thoughtful discussion.

SEX AND PARKINSON'S

Sexual function and satisfaction can stand alone from intimacy, but are very often improved by healthy intimate bonds. Compounding factors also affect sex such as age, stress levels, and communication patterns. Parkinson's disease and its medications can also have an effect in your sexual wellbeing.

The parts of the brain that can be impacted in Parkinson's control motor function, mood, hormone regulation, and reward-motivated behaviour. As a result, PD is associated with a number of symptoms that can impact sexual function, including:

- decreased sex drive, due to reduced dopamine supply
- · stiffness, tremors, slow movement, and dyskinesia, which impair sexual coordination
- Erectile Dysfunction, resulting from PD-related nervous system changes
- · vaginal dryness, and pain with intercourse
- · mental health conditions, stress, and self-esteem problems related to body image

Research suggests that many other factors can have more nuanced effects on the sexual health of people with Parkinson's and their partners. Shifting roles related to support and caregiving can change a couple's patterns of communication, and foster emotional conflict (Vatter et al., 2018). The decreased ability to show and mirror emotion in Parkinson's can cause confusion, a lack of spontaneity, and distance from their partners (Wootton et al., 2019).

Changes in body image and appearance can decrease confidence, while incontinence and urinary frequency can further contribute to self-consciousness and discomfort. Depression, amotivation, anxiety, and shame can stifle the urge for sex and foster emotional isolation.

Alongside PD symptoms themselves, medications can also impair physical stimulation and climax, or they may create hypersexuality (Bronner et al., 2018). Hypersexuality is one of a broad range of impulse control disorders in Parkinson's, attributed to dopamine agonists. If you or your partner notice issues with hypersexuality, talk to your doctor immediately.

SUPPORT FOR SEXUAL HEALTH

Parkinson's brings many changes that can lead to a significant shift, or even a halt in sexual activity, for many sexual partners. However, a balance can be restored around sex when it is seen as a process that involves the entire body and mind, and a healthy, intimate connection.

Parkinson Society BC offers free, short-term counselling for people with Parkinson's and their loved ones. Our counsellors can also support couples in navigating issues around their intimacy and sexual health. For more information, visit www.parkinson.bc.ca/counselling.

DISCUSSION: INTIMACY & SEXUAL HEALTH

ADDITIONAL RESOURCES

Sexual Intimacy | Helpsheet | bit.ly/pdintimacy

Young Onset Parkinson's Intimacy and Sexual Health | vimeo.com/116124115

Sexual & Reproductive Health | Michael J. Fox Foundation | bit.ly/3awjo1f

Sexuality & Intimacy | Davis Phinney Foundation | bit.ly/2RCzGwM

SOURCES

Bronner, G., & Korczyn, A. D. (2018). The Role of Sex Therapy in the Management of Patients with Parkinson's Disease. Movement disorders clinical practice, 5(1), 6-13.

Vatter, S., McDonald, K. R., Stanmore, E., Clare, L., McCormick, S. A., & Leroi, I. (2018). A qualitative study of female caregiving spouses' experiences of intimate relationships as cognition declines in Parkinson's disease. Age and ageing, 47(4), 604-610.

Wootton, A., Starkey, N. J., & Barber, C. C. (2019). Unmoving and unmoved: experiences and consequences of impaired non-verbal expressivity in Parkinson's patients and their spouses. Disability and rehabilitation, 41(21), 2516-2527.

PARKINSON'S AWARENESS MONTH

BE A PART OF OUR APRIL AWARENESS CAMPAIGN!

We are inviting members of the Parkinson's community to take part in our **#MoreThanATremor** campaign this April by sharing their stories, and helping spread awareness of the realities of life with PD.

Are you interested in taking part, or have any questions? Contact Jovana Vranic, Marketing & Communications Senior Coordinator, at jvranic@parkinson.bc.ca.