

A MONTHLY NEWSLETTER BY PARKINSON SOCIETY BC NOVEMBER 2019 ISSUE

CELEBRATING 50 YEARS OF SERVICE!



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 and impact stronger 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.

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 contact us at info@parkinson.bc.ca or 1-800-668-3330 for more details.

YOUNG ONSET PARKINSON'S DISEASE | WEBINAR SERIES

Young Onset Parkinson's Disease (YOPD) is generally defined as a diagnosis of Parkinson's before the age of 60. Because of the age of diagnosis, the needs of those with YOPD will differ from those with later-onset Parkinson's. Elaine Book, social worker at Pacific Parkinson's Research Centre, joins Parkinson Society BC for this webinar series aimed at addressing some of the specific issues faced by people affected by YOPD.

We encourage participants to bring their questions to each session as there will be time set aside for Q&A and discussion. We welcome all individuals with YOPD to this webinar series 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.

Registration information is available at www.parkinson.bc.ca/yopd-webinar-series.

Instructions on how to access the presentations will be sent out 24 hours before the event start time.

Self-Management

Self-management refers to the tasks that an individual must undertake to live well with one or more chronic conditions. It is particularly important for people with YOPD as Parkinson's is a lifelong progressive neurological illness. This session will go over self-management techniques to help you live well and thrive.

Date: Thursday, November 7 Time: 7:00pm - 8:00pm

Cost: Free

Coping as a Carepartner

This session will be co-facilitated by a carepartner of a YOPD individual and will cover some of the feelings and challenges that a carepartner of someone with YOPD may experience. Methods for coping will also be discussed.

Date: Thursday, November 14 Time: 7:00pm - 8:00pm

Cost: Free

Parenting

One of the unique challenges of YOPD is that those diagnosed are often parents to young or adolescent children. In this session, co-facilitated by a YOPD parent, we will discuss how children may be affected by a Parkinson's diagnosis in the family and how parents are able to support their children in this journey.

Date: Thursday, November 21 Time: 7:00pm – 8:00pm

Cost: Free

COMMUNICATION & SWALLOW WORKSHOP | WHITE ROCK

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, November 16

Time: 10:00am - 2:30pm (check-in begins at 9:30am)

Location: Hazelmere Golf & Tennis Club

18150 8th Ave, Surrey [map] Members: \$25 | Pair \$40

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

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

Registration: <u>www.parkinson.bc.ca/white-rock-cs</u>

ASK THE EXPERT: HOSPITALIZATION & PARKINSON'S | WEBINAR

People with Parkinson's disease (PD) have unique needs and considerations while in the hospital, and it is not uncommon for healthcare professionals to be unfamiliar with these needs. It is important for people with Parkinson's to be prepared for both planned and unplanned hospital visits, and to know how to self-advocate for their care.

Debra Mayer will be joining PSBC for the first time to discuss hospitalization and PD, share tips for how to best self-advocate in the hospital setting, and how you can make the most out of your <u>Aware in Care kit</u>. Debra is a member of the Aware in Care advisory committee at the Parkinson's Foundation, and is a registered nurse specializing in critical care and emergency nursing. Her areas of practice include chronic and acute care nursing, clinical experiences, and simulation. She also teaches nursing full-time.

Instructions on how to access the presentation will be sent our 24 hours before the event's start time.

Date: Tuesday, November 19 Time: 11:30am – 12:30pm

Cost: Free

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

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

FUNDRAISING EVENTS



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

NEWS & ANNOUNCEMENTS

NEW SUPPORT GROUPS

These groups are intended for anyone affected by Parkinson's disease. Carepartners, friends, and family members are welcome!

Richmond Princeton Williams Lake

1st Sunday of each month 1st Thursday of each month This is an informal group that meets 1:00pm - 2:00pm 3:30pm - 4:30pm irregularly.

Minoru Centre for Active Living [map] Princeton General Hospital [map]

(Wellness Studio) (Education Room) 7191 Granville Ave 98 Ridgewood Drive Please contact PSBC to find out more information!

Online Advanced Parkinson's Carepartners

This new monthly online support group is geared for individuals who care for someone with advanced Parkinson's disease, which can be characterized by complex medical needs and/or changes in cognition that require help in almost all areas of daily life.

Whether you are a spouse, partner, adult child, or friend, Parkinson Society BC invites you to join our growing online community, fostering connection with others who share similar experiences. To register, please contact Tricia Wallace at pwallace@parkinson.bc.ca or 1-800-668-3330.

Date: 4th Thursday of every month

Time: 9:00am - 10:30am

Location: Via webinar. A valid internet connection will be required to participate.

Login instructions will be sent out 24 hours before the meeting.

Cost: Free

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 2019.

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

INFORMATION KIOSK AT THE PACIFIC PARKINSON'S RESEARCH CENTRE

Every Thursday, Parkinson Society British Columbia will be available to provide information and consultations to those visiting the Movement Disorders Clinic at the Pacific Parkinson's Research Centre. Our friendly and knowledgeable staff can offer educational resources, give referrals, and connect you with the support services you need. Find us in the private side room, just off the waiting area.

Location: Movement Disorders Clinic | Pacific Parkinson's Research Centre

UBC Hospital, 2221 Wesbrook Mall, Vancouver [map]

Website: <u>parkinsons.ubc.ca</u>

NEW VIDEOS: PARKINSON'S EXERCISE SERIES

This February, we ran a six-week online exercise class led by Naomi Casiro, PWR! Certified Physiotherapist, and founder of NeuroFit BC. Due to the popularity of this program, we have teamed up to re-release these exercise videos in high resolution for you to follow along at home, at your own pace. Watch the first video here: youtu.be/TCIUh9KshDs.

TIP JAR

Anti-slip tape strips are often made in contrasting colours, creating a strong line on steps. Although helpful for grip and visibility, these may trigger freezing. Instead, consider clear or neutral-coloured anti-slip tape, or use clear grit with paint on outdoor stairs.

DISCUSSION: NOVEMBER IS FALL PREVENTION MONTH

DISCUSSION QUESTIONS:

- 1. How do you evaluate and eliminate fall hazards in your home?
- 2. What do you do to prevent falling, or practice safe falls?

People with Parkinson's disease (PD) fall up to three times more frequently than their peers in the general population. In a large review, over one third of PD participants fell an average of 20.8 times per year (Allen et al., 2013). Although falls without significant injury may be frequent, they should not be considered benign. Falls are associated with lower quality of life, social isolation, decreased functional activity, and mortality (WHO, 2018), and they can happen to people with Parkinson's as well as their carepartners.

General factors associated with increased falls include unsafe environments, increasing age, medical conditions (especially cardiac), physical inactivity, and foot function – including mobility and pain (Awale et al., 2017). The World Health Organization (2018) also cites medication side effects and alcohol consumption as factors in fall risk. For carepartners, assisting their loved ones with moving or repositioning can pose a notable risk.

Wherever you are in your journey with Parkinson's, it is important to be aware of potential hazards in your home. Fall risk can be significantly reduced by maintaining a safe environment. Floors and walkways should always be clear and free of clutter. Throw rugs can be a tripping hazard, but if you do not wish to remove them, they should be taped down with an adhesive. Furniture should be firm, with good back support, and at a height that is easy to get up from. Everyday items should also be within easy reach, between hip and eye level.

Fall risk can also be mitigated with good symptom management. Many people with PD may be at greater risk during medication "off" times, or when experiencing mental health changes and fatigue. See below for key motor and non-motor symptoms associated with falls in PD.

MOTOR SYMPTOMS

- balance, posture, and stability (swaying easily)
- retropulsion (backwards falling)
- gait (shorter stride time and variability in stride)
- · muscle weakness
- freezing of gait
- dyskinesia

NON-MOTOR SYMPTOMS

- decision-making ability (ambivalence, impulsivity)
- anxiety (affects problem-solving and tolerance toward stimuli)
- fear of falling (increases with repeated falls, and results in inactivity)
- visual impairment (medication side effects, eye movement, and perceptual changes)
- low blood pressure (hypotension)
- fatigue and sleep problems
- · urinary incontinence

Follow the P's for prevention of falls:

- Pause: take a deep breath and consider stages when making transitions
- Personal Care: don't rush to the toilet; set up room and clothing for access
- Pills: review medications; prepare for 'wearing off'; take meds on time
- Pull wide "U-turns" around corners and get support with transitions
- Possessions: keep them in reach; use a waist pack instead of purse/bag
- · Physical activity: keep moving; maintain or build muscle strength
- Purposeful interactions: tell someone if you have fallen, and remain social
- Posture counts: address postural changes in blood pressure by waiting 5 seconds after standing up before taking a step

Increasing your knowledge about risk patterns allows you to identify and address key areas of need which can improve safety and confidence around mobilization while boosting quality of life. Talk with your family and friends, and contact your healthcare team for tips on fall risk assessment and prevention.

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ADDITIONAL RESOURCES

Screening & assessment tools | Fall Prevention Task Force | bit.ly/fallsassessment

A-Z Fall Risk Factors | Saskatoon Health | bit.lv/azfallrisk

Maximize Your Mobility | Davis Phinney Foundation | vimeo.com/147745733

In-Home Safety Checklist | PSBC | bit.ly/InHomeSafetyCheck

Physical Activity Guidelines | PSBC | bit.lv/PDPhysicalActivity

Parkinson's Exercise Video Series | PSBC | youtu.be/TCIUh9KshDs

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Nocera, J. R. et al. (2013). Using the timed up & go test in a clinical setting to predict falling in Parkinson's disease. Archives of Physical Medicine and Rehabilitation, 94(7), 1300-1305.

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