

PSBC MEMBERSHIP RENEWAL

September 1 marks the beginning of the membership renewal period for 2018 with Parkinson Society British Columbia. Membership is only \$25 per household and is valid from the time of renewal until December 31, 2018. Learn more about membership benefits, including how you can get your new exclusive members only lapel pin on our website: www.parkinson.bc.ca/membership

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 Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 for more details.

NEW PILOT PROJECT! ONLINE CAREPARTNER SUPPORT GROUP

This new monthly online support group is especially geared for individuals who care for someone with Parkinson's disease. Whether you are a spouse, partner, adult child, or friend, Parkinson Society British Columbia invites you to join our growing online community of support.

Start Date: Every third Wednesday of the month, beginning September 20
 Time: 9:00am – 10:00am
 Location: Via webinar. *A valid internet connection will be required to participate.*
 Contact: Myriame at mlepinelyons@parkinson.bc.ca or 1-800-668-3330.

COMMUNICATION AND SWALLOW WORKSHOP (COURTENAY/COMOX)

This full-day 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 (PwP). 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, September 23
 Time: 10:00am – 2:30pm
 Location: Crown Isle Resort & Golf Community
 399 Clubhouse Drive, Courtenay ([map](#))
 Fees: Member \$40.00 | Member (Couple/Pair) \$70.00
 Non-Member \$50.00 | Non-Member (Couple/Pair) \$90.00
 Registration: www.parkinson.bc.ca/courtenay-comox-communication-swallow

COMMUNITY TALK: EXERCISE AND MEDICATION MANAGEMENT FOR PEOPLE WITH PARKINSON'S (VERNON)

Join Parkinson Society British Columbia (PSBC) as we host an afternoon of education. Speakers will discuss the importance of exercise and tips on medication management for people with Parkinson's disease (PD). Attendees will also have the opportunity to try boxing!

Speakers include:

- Cheryl Daniels, a nurse from the Kelowna MS and Movement Disorders Clinic who will be speaking about medication types and management.
- Mary de Souza, a PWR! Certified Instructor and member of PSBC's speaker's bureau. She will lead the exercise component of the afternoon and discuss the importance of exercise for managing symptoms of Parkinson's disease.
- Antony Stamboulieh, a NCCP Level 3 accredited boxing coach and former President of the BC Boxing Association, will lead the group in boxing and voice exercises. Antony will also provide information about the local boxing program.

Date: Saturday, October 14
 Time: 1:00pm – 3:30pm (registration opens at 12:30pm)
 Location: Vernon Lodge & Conference Centre
 3914 32nd Street, Vernon ([map](#))
 Fees: Member \$5.00
 Non-member \$10.00
 Registration: www.parkinson.bc.ca/vernon-community-talk

COMMUNITY TALK: MEDICATION MANAGEMENT (CRANBROOK)

PSBC will host an evening education event with Cheryl Daniels, a nurse from the Kelowna MS and Movement Disorders Clinic. Cheryl will be speaking about medication management and Parkinson's disease.

Date: Wednesday, October 18
 Time: 7:00pm – 8:00pm
 Location: Heritage Inn Hotel & Convention Centre - Annex Room
 803 Cranbrook Street North, Cranbrook ([map](#))
 Capacity: 15
 Cost: Free
 Registration: www.parkinson.bc.ca/cranbrook-community-talk

ASK THE EXPERT WEBINAR SERIES: DEEP BRAIN STIMULATION FOR PEOPLE WITH PARKINSON'S

People with Parkinson's have areas of their brain that are overactive. Deep Brain Stimulation (DBS) is a procedure that may correct this by blocking electrical signals from targeted areas in the brain. Those who have this surgery may see improvements in their symptoms including tremor, dyskinesia and motor fluctuations. To learn more about this surgical procedure, join us on October 24, for our first presentation in partnership with the Deep Brain Stimulation (DBS) Clinic at the University of British Columbia.

Date: Tuesday, October 24
 Time: 10:00am – 11:00am
 Location: Via webinar. *A valid internet connection will be required to participate.*
 Cost: Free
 Registration: www.parkinson.bc.ca/deep-brain-stimulation-webinar

DEBRIEFING THE CAREPARTNER ROLE

When a loved one is lost, it is one of life's most difficult experiences. You may find yourself struggling with many intense and frightening emotions leaving you feeling isolated or alone. Having someone to lean on in this time is important in helping you through the grieving process.

In collaboration with the Pacific Parkinson's Research Centre, please join us at this workshop, with Elaine Book, Social Worker at the Pacific Parkinson's Research Centre, and Myriame Lépine Lyons, Clinical Counsellor at PSBC.

Date: Thursday, October 26
 Time: 12:00pm – 2:00pm
 Location: Kensington Branch – Vancouver Public Library
 1428 Cedar Cottage Mews, Vancouver ([map](#))
 Cost: Free
 Registration: www.parkinson.bc.ca/caregiver-grief-session

COMMUNITY TALK: COGNITIVE CHANGES WITH PARKINSON'S (NANAIMO)

In the later stages of Parkinson's disease (PD) some people may experience cognitive changes including difficulties with attention, task completion, decision-making, problem solving, memory and word-finding. These symptoms can be very frustrating but may not, in the early stages, have a serious impact on one's daily life. As with all symptoms of PD, everyone is different.

Join Dr. Kaitlyn Roland on October 27 for a presentation that will address cognitive changes for people with Parkinson's. The session will begin with some light, seated yoga led by local yoga instructor, Laura Frey.

Date: Friday, October 27
Time: 1:30pm – 3:00pm (registration opens at 1:00pm)
Location: Beban Park Recreation Centre - Meeting Rooms 1 & 2
2300 Bowen Road, Nanaimo ([map](#))
Cost: Free
Registration: www.parkinson.bc.ca/nanaimo-community-talk

NEWLY DIAGNOSED WEBINAR SERIES: WHAT YOU WANT TO LEARN TODAY TO BETTER YOUR TOMORROW

Everyone responds in a different way when told they have Parkinson's disease. For some, the diagnosis may be a relief. Others may find themselves in denial and need some time to accept the diagnosis. When adjusting to a diagnosis, people may experience a wide variety of emotional reactions is common. You will likely have questions about how to cope and what the future may hold. This webinar series will attempt to answer some of these questions.

If you have been newly diagnosed with Parkinson's disease, we invite you to join Parkinson Society British Columbia (PSBC) and special guests for a 4 week webinar series every Friday in November.

Date: Every Friday in November, beginning November 3
Time: 10:00am – 11:00am
Location: Via webinar. *A valid internet connection will be required to participate.*
Cost: Free
Registration: www.parkinson.bc.ca/newly-diagnosed-webinar-series

COMMUNICATION AND SWALLOW WORKSHOP (CHILLIWACK)

This full-day 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 (PwP). 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 4
Time: 10:00am – 2:30pm
Location: Best Western - Rainbow Country Inn
43971 Industrial Way, Chilliwack ([map](#))
Cost: Member \$40 / Members (Pair) \$70
Non-member \$50 / Non-members (Pair) \$90
Registration: www.parkinson.bc.ca/chilliwack-communication-swallow

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

Champions FOR PARKINSON'S

- Cotswolds Walking Holiday: August 31 – September 8 ([donate](#))
- #BeerParky: September 23 ([read more](#))
- TeaParky: Ongoing ([read more](#))

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 at mdzaferovic@parkinson.bc.ca or 1-800-668-3330.

PARKINSON SUPERWALK



Have you registered for Parkinson SuperWalk yet?

The largest fundraising event of the year is coming up fast! Beginning the weekend of September 9 and 10, incredible British Columbians in over 20 communities throughout the province will walk together to help give hope to 13,000 people in BC living with Parkinson's disease.

Register or donate today at www.parkinson.bc.ca/superwalk

Real British Columbians talk about why they walk in the following video: <http://bit.ly/parkinsonsuperwalkbcvideo>

Special thanks to provincial sponsor Global for their support!



JACLYN WILLEMS JOINS THE PSBC TEAM!

Jaclyn Willems is the newest staff on the Education and Support Services team, assisting while Stacey Dawes takes maternity leave. Originally from Abbotsford, Jaclyn pursued a Diploma in Social Work in Calgary, AB. For the past few years, she has worked as a family support intake worker and as a community resource worker. Jaclyn has ample experience being the first point of contact in an organization, supporting individuals in crisis and providing support, referrals and resources to inquirers. You can reach Jaclyn at jwillems@parkinson.bc.ca or by calling the Society at 1-800-668-3330.

GRANDPARENTS DAY – SEPTEMBER 10

In 1970, American Marian McQuade started a campaign to establish a national day to honour grandparents in the United States. In 1978, President Jimmy Carter declared the first Sunday after Labour Day to be National Grandparents Day in the US. Canada followed suit in 1995. The three purposes for Grandparents Day are to honour grandparents; to give grandparents an opportunity to show love for their grandchildren, and to help children become aware of the strength, information and guidance their grandparents can offer. Learn more at <http://www.legacyproject.org/guides/gpdhistory.html>.

RESEARCH STUDY – BIOMEDICAL TECHNOLOGY FOR INDIVIDUALS WITH PARKINSON'S DISEASE

This study is designed to investigate the effect of Galvanic Vestibular Stimulation (GVS) on the gait (i.e. manner of walking) of individuals with Parkinson's disease. GVS is a non-invasive technique that has been used in healthy individuals and individuals with stroke and PD. The testing protocol will be performed at the Simon Fraser University (SFU) Surrey or Burnaby campus, or City Centre 1 (CC1, Surrey), or during a home visit. For more information, please contact Bindu Mohan at bmohan@sfu.ca or 778-782-5188.

DISABILITY ALLIANCE BC – FREE WORKSHOPS

Disability Alliance BC (DABC) provides workshops across the province to share information on provincial and federal (CPP-D) disability benefits, the Registered Disability Savings Plan (RDSP), Disability Tax Credit (DTC), income tax filing and emergency preparedness. Most workshops are provided free of charge, across BC. However, they ask that a minimum of 10 participants be confirmed for workshops outside Metro Vancouver. Learn more at <http://disabilityalliancebc.org/>.

ROCK STEADY BOXING – SURREY

Classes are based on non-contact boxing based training. Workouts may include, but are not limited to, shadow boxing, focus mitts, heavy bags, jump rope, stationary biking, core work, calisthenics and circuit weight training. This program is designed for men and women with any stage of Parkinson's disease.

Date: Monday – Friday, ongoing basis
Time: 11:30am – 12:30pm
Location: Box2Fit | 1160 King George Boulevard, Surrey ([map](#))
Cost: \$150/One Month Unlimited or \$15/Class
Capacity: \$20 participants
Registration: Contact Frankie LaSasso (Certified Rock Steady Boxing Coach) at 778-382-6284 or box2fitsurrey@rsbaffiliate.com

DANCE FOR PD (COQUITLAM)

Date: Thursdays | September 21 - December 7
Time: 10:30am – 11:30am
Location: Place des Arts | 1120 Brunette Avenue, Coquitlam ([map](#))
Cost: \$141
Discount: Register online, by phone or in person using coupon code 50OFF to receive 50% off your adapted program registration. One coupon per student.
Registration: www.placedesarts.ca | 604-664-1636 ext. 0

SUPPORT GROUP FACILITATOR NEEDED IN SURREY!

Are you a Surrey resident interested in facilitation, socializing and supporting people affected by Parkinson's disease? We are looking for a Parkinson's Support Group Facilitator in Surrey! For more information, please contact Caroline Wiggins at cwiggins@parkinson.bc.ca or 1-800-668-3330. <http://ow.ly/JfZf30eaNYO>

EXERCISE

Our website includes an up-to-date list of all of the Parkinson's-specific community exercise programs across the province – there may be one near you!

<https://www.parkinson.bc.ca/exercise>

**TIP JAR**

Wendy, who is part of the Parkinson's community here in British Columbia, swears by a software called "Steady Mouse" (<https://www.steadymouse.com>). It is a downloadable software that stabilizes the mouse icon for people who have a hand tremor. The current version costs approximately \$43 USD (\$54 CAD). It can even be easily turned on and off, allowing people with Parkinson's who use the software to share their computers with other members of their household.

Wendy claims that the difference between using the computer before and after using the software is like "night and day". Her confidence in using the computer is back thanks to Steady Mouse.

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 Myriame at mlepinelyons@parkinson.bc.ca or 1-800-668-3330.

SUBSCRIBE TO GROUPLINK!

If you wish to receive personal copies of GroupLink please connect with Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 and your name will be added to our GroupLink email distribution list.



DISCUSSION QUESTIONS

1. Have you experienced or witnessed symptoms associated with Mild Cognitive Impairment (MCI)? If so, what were they?
2. What are some strategies/mechanisms that can be useful to someone with Mild Cognitive Impairment?
3. How can we reduce stigma and improve communication about cognition challenges in our daily lives?

As Parkinson's disease (PD) advances, about 50% of people with PD will experience some cognitive decline. However, only 30% of people with Parkinson's will develop Parkinson's related dementia in the advanced stages of the disease (Parkinson Society British Columbia, 2016).

WHAT CAUSES MILD COGNITIVE IMPAIRMENT (MCI)?

A drop in dopamine, which regulates the body's movements, can cause mild and circumscribed cognitive changes.

Scientists are currently examining changes in two other neurotransmitters called acetylcholine and norepinephrine as possible causes of decline or changes in mental control, self-regulation and memory loss (PDF, 2017).

WHAT MIGHT MCI LOOK LIKE?

The following are some of the symptoms affiliated with MCI:

- Forgetting things more often
- Forgetting important events such as appointments or social engagements
- Losing trains of thought or experiencing problems following storylines in conversations, books or movies
- Feeling increasingly overwhelmed by making decisions, planning steps to accomplish a task or interpreting instructions
- Experiencing difficulty navigating familiar environments
- Becoming increasingly impulsive or showing increasingly poor judgement
- Family and friends noticing any of the above behaviours (Mayo Clinic Staff, 2017)

A MCI diagnosis may be made when an individual is able to perform all their usual activities successfully, without more assistance from others than they previously required. However, regular follow up is recommended to ensure that there is no progression of any impairments (UCSF Memory and Aging Center, 2017). Fernandez et al. (2005) state that: "when differences in cognitive decline are subtle, like that in PD patients with MCI, appreciating cognitive changes that may be due to medications is essential. Appropriately timing neuropsychological testing to on and off medication periods needs to be recorded for appropriate cognitive monitoring and MCI diagnosis".

TREATING MCI IN PD

If you report changes of cognition to your doctor, your doctor should rule out causes of MCI other than Parkinson's, such as vitamin deficiency, depression or fatigue. Parkinson's does not typically cause a sudden change in cognition and, if someone experiences this, the cause is likely something else, like a medication side effect.

Drug therapies available for cognitive changes that have been professionally diagnosed as symptomatic of Parkinson's include rivastigmine, donepezil and galamantine. Individuals experiencing attention difficulties due to daytime sleepiness may benefit from stimulants (PDF, 2017).

TAKEAWAYS

- MCI **is not** exclusive to people with Parkinson's disease, although PD (or PD medications) are sometimes a direct cause of MCI.
- MCI **does not** decrease the worth or intelligence of an individual.
- MCI **should** be closely monitored.

It can be difficult for you, as a carepartner, to know how to approach the topic of cognitive impairment and assist your loved one. Sometimes the best thing to do is just listen and show that you care. Our helpsheet on [Communicating Effectively with a person with Parkinson's who has Cognitive Impairments](#) as well as the American Family Caregiver Alliance (www.caregiver.org) have some useful tips for enhancing communication with a person experiencing cognitive impairment:

- Speak slowly, clearly and carefully: Speak to the person as an adult, but make a conscious effort to speak slowly and clearly. Use real names instead of pronouns, to remind your loved one who you are speaking about.
- Ask closed-ended questions: Closed-ended questions which elicit a “yes”, “no” or “maybe” could be more effective than open-ended questions. For example, “Are you ok?” may be more effective than “How are you doing?”
- Encourage exchange: Make conversations a two-way process that engages the person. Avoid interrupting or answering questions directed at the person with PD, which may discourage them from communication. Be patient and assist them with finding the right words if they seem to be struggling.
- Choose the best time to communicate: “Off” periods (when medication is not managing symptoms effectively), excessive day-time sleepiness and periods of anxiety/depression may not allow for effective communication. Be patient with your loved one. Understand that a person with PD may feel frustrated, anxious or sad at the loss of some abilities.
- Learn more about Mild Cognitive Impairment (MCI) and share that knowledge with those around you.
- Discuss with a family member, or other trusted person, your loved one’s preferences for decisions affecting their life, should the MCI progress to dementia.
- Find constructive ways to release anger and frustration you may feel. Exercise, talk with a close friend or a PSBC clinical counsellor.
- Use visible and/or accessible reminders.
- Become an advocate for your loved one and other individuals with MCI.
- Focus on what you can do, not on what you can’t (Family Caregiver Alliance et. al., 2011).

Want to chat with other carepartners about caregiving challenges?

Consider joining our new Online Carepartner Support Group hosted via webinar on every 3rd Wednesday of the month, beginning September 20th, from 9:00am – 10:00am. Please contact Myriame at mlepinelyons@parkinson.bc.ca or 1-800-668-3330 for more information.

Sources

Family Caregiver Alliance et. al. (2011). Mild Cognitive Impairment. Retrieved from <https://www.caregiver.org/mild-cognitive-impairment-mci>.

Mayo Clinic Staff. (2017). <http://www.mayoclinic.org/diseases-conditions/mild-cognitive-impairment/symptoms-causes/dxc-20206111>.

Parkinson's Disease Foundation, Inc. (PDF). (2017). Cognitive Impairment. Retrieved from http://www.pdf.org/cognitive_impairment_pd.

Parkinson Society British Columbia. (2016, April 26). Communicating Effectively with a Person with Parkinson's who has Cognitive Impairments. Retrieved from <https://www.parkinson.bc.ca/media/31533/pd-dementia-and-communication-challenges.pdf>.