

# GROUPLINK 1

UPCOMING EVENTS | NEWS & ANNOUNCEMENTS | DISCUSSION TOPIC | CAREPARTNER'S CORNER **OCTOBER 2017**

**The Parkinson Society British Columbia (PSBC) office will be closed on Monday, October 9 for Thanksgiving.**

## 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](mailto: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 (PD). 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  
 Time: 9:00am – 10:00am  
 Location: Via webinar. *A valid internet connection will be required to participate.*  
 Contact: Myriame at [mlepinelyons@parkinson.bc.ca](mailto:mlepinelyons@parkinson.bc.ca) or 1-800-668-3330.

### 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 provide 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](http://www.parkinson.bc.ca/vernon-community-talk)



### COMMUNITY TALK: MEDICATION MANAGEMENT (CRANBROOK)

Join PSBC for a community talk with Cheryl Daniels, a nurse from the Kelowna MS and Movement Disorders Clinic. Cheryl will be speaking about medication management for 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](http://www.parkinson.bc.ca/cranbrook-community-talk)

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### 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 and Nancy Polyhronopoulos, RN, 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: <https://www.parkinson.bc.ca/deep-brain-stimulation-webinar>

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### DEBRIEFING THE CAREPARTNER ROLE

Losing a loved one 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, 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](http://www.parkinson.bc.ca/caregiver-grief-session)

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

In the later stages of Parkinson's disease, 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 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](http://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, identifying the cause of physical and mental changes may come as a relief. Others may find themselves in denial and need time to adjust. 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 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](http://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](http://www.parkinson.bc.ca/chilliwack-communication-swallow)

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

# Champions FOR PARKINSON'S

- THOUGHTS R LIFE Apparel: Online apparel sales benefitting PSBC, ongoing ([read more](#))
- Parkinson Society BC's Fall Auction: Online auction, November 1 - 15, details TBA
- TeaParky: 33% of proceeds from every sale on [TeaParky.com](http://TeaParky.com) will go to PSBC, ongoing.

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](mailto:mdzaferovic@parkinson.bc.ca) or 1-800-668-3330.

## OCTOBER 1<sup>ST</sup> IS NATIONAL SENIORS DAY IN CANADA

The Government of Canada celebrates this day because it formally recognizes and raises awareness of the importance of contributions seniors have made in shaping this great nation. The Government of Canada is working hard to help improve the lives of seniors on many fronts, including the following:

- **Increasing benefits for couples living apart for reasons beyond their control**  
Amendments to the Old Age Security Act will be introduced to ensure that couples who receive Guaranteed Income Supplement (GIS) and Spouse's Allowance, who live apart for reasons beyond their control (such as a requirement for long-term care), will receive higher benefits based on their individual incomes, not combined incomes.
- **Supporting affordable housing for seniors**  
The Government will support the construction, repair and adaption of affordable housing for low-income seniors through an investment of \$201 million over two years starting in 2016-2017 to help the many seniors facing challenges in accessing affordable housing. While funding is being provided under the Investment in Affordable Housing (IAH) initiative, provinces and territories will not be required to cost-match these investments.

To learn more, visit <https://www.canada.ca/en/employment-social-development/campaigns/national-seniors-day.html>

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## SUPPORT GROUP FACILITATOR NEEDED IN SURREY!

We are looking for a Parkinson's Support Group Facilitator in Surrey. For more information, please contact Caroline Wiggins at [cwiggins@parkinson.bc.ca](mailto:cwiggins@parkinson.bc.ca) or 1-800-668-3330. Learn more about this volunteer position here: <http://ow.ly/JfZf30eaNY0>

## 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>

**Note:** Any listing 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.



## TIP JAR

Games! Games! And more games! Ever find yourself looking for something to occupy your time when waiting for the bus? Do you need a brain activator in the morning? Want to play tennis in your living room? Maria, a new PD community member, has some shared some great gaming application suggestions.

For your phone:

- [Peak Brain Training](#)
- [Beats Medical Parkinson's Treatment](#)

For your home:

- PWR! Moves at-home [Youtube videos](#)
- NeuroFitBC [YouTube videos](#)
- Nintendo Wii: [some research](#) has shown that the Wii may help improve balance and mobility in patients with PD

If you live in the Lower Mainland and are interested in playing cards or games connect with PSBC at [info@parkinson.bc.ca](mailto:info@parkinson.bc.ca)!



PWR! Drumming with Jenn

237 views

7 0 SHARE

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 [mlepinyons@parkinson.bc.ca](mailto:mlepinyons@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](mailto:cwiggins@parkinson.bc.ca) or 1-800-668-3330 and your name will be added to our GroupLink email distribution list.

## DISCUSSION QUESTIONS

1. How have seasonal changes affected your mood, if at all?
2. What attitude or behavioural changes have you noticed as a result of Parkinson's disease, if any?
3. What have you done or could you do to help manage mood changes in yourself or a loved one?

"Mood changes" is an umbrella term that encompasses a number of non-motor symptoms of Parkinson's disease, such as anger, anxiety, depression and increased irritability. People with Parkinson's often experience changes in their moods, perhaps even before diagnosis. Due to the varied nature of mood changes, this article will focus on depression, anxiety and apathy – three conditions commonly experienced by those with Parkinson's disease.

## WHY DO PEOPLE WITH PARKINSON'S EXPERIENCE MOOD CHANGES?

1. **The Disease Experience.** Those affected by Parkinson's, including the diagnosed individual as well as their friends and family, will find themselves dealing with a range of emotions. As symptoms change and progress, new emotions may emerge. It is normal to be worried about your symptoms and to wonder what is coming in the future.
2. **Biology.** Parkinson's is sometimes referred to as a neuropsychiatric disease. This is because it affects the nervous system ("neuro") while also involving changes in mental health ("psychiatric"). Neurotransmitters, such as dopamine, regulate movement as well as mood. People with Parkinson's are at an exceptionally high risk of experiencing mood fluctuations due to the underlying chemical and biological nature of the disease.
3. **Medication.** Some medications used to manage Parkinson's disease can affect one's mood. For example, some dopamine agonists may lead to impulsive behaviours. Drug interactions can also impact mood. If you think your medications may be impacting your temperament, it is important to speak with your physician as early as possible.
4. **External Factors.** Like everyone, your everyday environment can impact your mood. The weather, household finances, work or family life can take its toll (Minton et. al., 2017).

## DEPRESSION AND ANXIETY

At least 50% of people with Parkinson's disease experience depression and/or anxiety, which have been proven to affect an individual's ability to respond positively to treatment. If you feel depressed or anxious, it may be difficult to do the things that are critical to managing PD, such as socializing with family and friends, exercising, eating well and many others activities of daily living that you would normally enjoy.

A variety of effective treatment options are available to help with depression and anxiety. Here are some important points to consider:

- **FIRST:** remember that depression and anxiety are real illnesses, they are actual symptoms of PD and they can be treated.
- Listen to your family and your physician if they suggest that you might be depressed or having difficulty coping with daily life or Parkinson's treatments.
- There are many types of medication for depression and anxiety. If medications are an option you are exploring with your healthcare team, do not be afraid to ask about your options.
- If you start taking medication for depression or anxiety, remember that it can take several weeks before you feel better. Early side effects usually disappear as your body gets used to the new drug. It is important to keep your physician informed as to what side effects you may be experiencing.
- You need the support of your family and friends at this time. Ask for help, even a casual conversation can be incredibly helpful.
- Contact PSBC's Clinical Counsellors by calling 1-800-668-3330 or emailing [counselling@parkinson.bc.ca](mailto:counselling@parkinson.bc.ca). The Society provides a free, confidential, short-term counselling service to those affected by Parkinson's (PSBC, 2016).
- Parkinson Society BC also provides a [help sheet on depression and anxiety](#), available online.



## APATHY

People who experience apathy are, generally, less interested in taking part in activities that help maintain their level of functioning. Apathy affects approximately 40% of people with Parkinson's. Greater understanding of apathy and Parkinson's is very important for individuals with PD and members of their support network.

Apathy manifests itself across different domains. Some of the behavioural changes it may cause include:

- reduced interest in people and activities
- reduced spontaneous interactions with others or with pets
- lack of motivation and decreased initiation of activities
- flat/dampened affect (an inability to express emotions)
- changes in mood and thinking
- little or no goal-directed behaviour

Exercise and the establishment of a regular activity and sleep schedule are the best lifestyle changes that can be implemented if an individual is experiencing apathy. In consultation with a medical professional, a limited number of prescribed medications may be explored as treatment options (PSBC, 2016).

For more information about Apathy, read the [Apathy and Parkinson's](#) online help sheet.

## CAREPARTNER'S CORNER

Carepartners/caregivers are prone to mood changes as well. In 2015, Office of the Seniors Advocate British Columbia reported that 29% of unpaid carepartners/caregivers experience symptoms of distress, such as anger, depression or feeling unable to continue to provide care. On August 30 of this year, they provided an update:

- In 2015/16, 31% of the office's clients had a primary caregiver in distress
- Over this period, the actual number of primary caregivers identifying as distressed increased by over 1,000, which represents a 14% increase in the actual number of carepartners/caregivers in distress
- The number of home support clients accessing Adult Day Programs decreased by 5% and the number of days delivered to these clients decreased by 2% (Office of the Seniors Advocate British Columbia, 2017)



Signs of distress include denial, anger, social withdrawal, anxiety, depression, exhaustion, sleeplessness, emotional reactions, lack of concentration and health problems (Alzheimer Society BC, 2014). If you experience any number of these symptoms, it may be time to reach out for help.

### HOW CAN YOU HELP YOURSELF?

Part of helping yourself is knowing what you need. Be honest with the level of care that you already provide or may need to provide. Can you do it? Can someone else help? Forming boundaries around the level of care will help you sort through different support services, such as hiring in-home support workers (with [Care BC](#), [Classic LifeCare](#), [We Care](#) or [Nurse Next Door](#), for example), signing up for [Adult Day Programs](#) through your local health authority, or obtaining [Home and Community Care](#) services, whether on an hourly timeframe at home or in a care facility for a week or two.

In this context, boundary setting can help you regain your sense of autonomy and improve your overall happiness. Watch the [Carepartner Connect – Regaining Autonomy webinar](#), hosted by Elaine Book, MSW from Pacific Parkinson Research Centre, to learn more about the emotions carepartners/caregivers face and how to regain your autonomy.

More of our caregiving resources are available online at: <https://www.parkinson.bc.ca/resources/#caregiving>

#### HOW CAN WE HELP YOU?

- Free short-term counselling is available to carepartners needing emotional support. To connect with one of the PSBC Clinical Counsellors, visit <https://www.parkinson.bc.ca/counselling> or call 1-800-668-3330.
- There are various carepartner/caregiver support groups across British Columbia. To see if one is located in your area, visit <https://www.parkinson.bc.ca/supportgroups> or call 1-800-668-3330. PSBC has also recently launched an Online Carepartner Support Group. Contact Myriame at 1-800-668-3330 or [mlepinelyons@parkinson.bc.ca](mailto:mlepinelyons@parkinson.bc.ca) to get the login instructions for the webinar meetings. Meetings are held every 3rd Wednesday of the month from 9:00am – 10:00am. The next meeting will take place on Wednesday, October 18.

#### Sources

Alzheimer Society BC. (2014, November 16). *10 Warning Signs of Stress*. Retrieved from <http://www.alzheimer.ca/en/bc/Living-with-dementia/Caring-for-someone/Self-care-for-the-caregiver/10-warning-signs-of-stress>

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