

# GROUPLINK 1

UPCOMING EVENTS | NEWS & ANNOUNCEMENTS | DISCUSSION TOPIC | CAREPARTNER'S CORNER **JANUARY 2018**

Please be advised that Parkinson Society British Columbia's office is closed for the holidays from Monday, December 25, 2017 through Monday, January 1, 2018 (inclusive).

## SUBSCRIBE NOW! RECEIVE GROUPLINK DIRECTLY TO YOUR INBOX

If you wish to personally receive GroupLink please connect with Caroline at [cwiggins@parkinson.bc.ca](mailto:cwiggins@parkinson.bc.ca) or 1-800-668-3330 and you will be added to the GroupLink e-mail distribution list.

## 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.**

### ASK THE EXPERT WEBINAR: LEGAL AID FOR DUTY TO ACCOMMODATE & DISABILITY INSURANCE

On January 30<sup>th</sup>, 2018, Eleni Kassaris, lawyer and partner at the law firm, Blake, Cassels & Graydon LLP, which provides our pro-bono legal services, will speak about employers' duty to accommodate and disability insurance.

The 'duty to accommodate' is a legal requirement arising out of human rights legislation and case law in Canada. Although the 'duty to accommodate' is not found in the BC Human Rights Code, a series of Supreme Court of Canada decisions confirm the duty exists and applies to all provincially regulated employers. Accommodation is an equality concept that seeks to build inclusive environments that respect the differences and rights of a diverse society. For example, where the capabilities of a person are restricted due to a disability, a reasonable accommodation, such as the purchase of an assistive device, or the restructuring of certain components of their job, may be required in order to allow for that person to apply their skills and abilities on a level playing field while still participating in the workforce. The goal of the 'duty to accommodate' is to enable to full and equitable participation of all members in society ([BC Human Rights Clinic](#), 2016).

Date: Tuesday, January 30, 2018  
 Time: 10:00am – 11:00am  
 Location: Via webinar. *A valid internet connection will be required to participate.*  
 Cost: Free  
 Registration: [www.parkinson.bc.ca/legal-aid-webinar](http://www.parkinson.bc.ca/legal-aid-webinar)

### ASK THE EXPERT WEBINAR: VISION ISSUES IN PARKINSON'S

People with Parkinson's experience a variety of symptoms, some of which are lesser known, including problems with their eyes and vision. Visual disturbances can be associated with the disease itself, or as a side effect of medications. Ophthalmologists can assist in determining the cause of the problem.

On February 20<sup>th</sup>, 2018, Jason Barton, neuro-ophthalmologist at St. Paul's Hospital and Professor of Medicine (Neurology) at the University of British Columbia, will join Parkinson Society BC (PSBC) for the first time to address issues with vision in Parkinson's disease.

Date: Tuesday, February 20, 2018  
 Time: 10:00am – 11:00am  
 Location: Via webinar. *A valid internet connection will be required to participate.*  
 Cost: Free  
 Registration: [www.parkinson.bc.ca/vision-webinar](http://www.parkinson.bc.ca/vision-webinar)

### TIME OUT FOR CAREPARTNERS WORKSHOP, NANAIMO

On February 24<sup>th</sup>, 2018, we invite carepartners/caregivers to join us for a day of education, socialization and relaxation. Expert speakers will share experiences and strategies for coping with the complexities that arise as a result of Parkinson's disease (PD). Lunch and light refreshments will be provided.

**SPECIAL NOTICE:** An adjacent room will be available for people with Parkinson's (PwP) to partake in activities (e.g., light exercise, games, socializing), while their carepartner participates in discussions with other carepartners. We ask that PwP coming to this event respect this room divide, and refrain from attending sessions intended for carepartners. This room will be managed by volunteers who will provide companionship and light exercise activities. **The volunteers will not be medical professionals.**

Date: Saturday, February 24, 2018  
 Time: 10:00am – 3:30pm  
 Location: Vancouver Island Conference Centre  
 101 Gordon Street, Nanaimo ([map](#))  
 Cost: Member \$30 / Members (Couple/Pair) \$45  
 Non-Member \$40 / Non-Members (Couple/Pair) \$55  
 Registration: [www.parkinson.bc.ca/TOFC-nanaimo](http://www.parkinson.bc.ca/TOFC-nanaimo)

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### COMMUNITY TALK: MEDICATION MANAGEMENT, VANCOUVER

On March 7<sup>th</sup>, 2018, join Parkinson Society British Columbia (PSBC) as we host an afternoon of education at the Italian Cultural Centre. Movement Disorder Specialist, Dr. Jonathan Squires, from Pacific Parkinson's Research Centre at UBC, will provide an overview of Parkinson's disease, treatment options and tips for medication management.

Date: Wednesday, March 7, 2018  
 Time: 1:30pm – 3:30pm  
 Location: Italian Cultural Centre – Trattoria Hall  
 3075 Slocan Street, Vancouver ([map](#))  
 Cost: PSBC Member \$5.00  
 PSBC Non-Member \$10  
 Registration: [www.parkinson.bc.ca/vancouver-community-talk](http://www.parkinson.bc.ca/vancouver-community-talk)

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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 24<sup>th</sup>, 2018, Parkinson Society British Columbia (PSBC) will be hosting 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 will include:

- Emergency Preparedness and Risk Management: Karen Martin, Disability Alliance and Rajpreet Sall, Emergency Management Community Liaison at the City of Victoria
- Enhancing Communications – Taking Care of Your Voice: Sue Decker, Registered Speech-Language Pathologist

Date: Saturday, March 24, 2018  
 Time: 1:00pm – 4:30pm (registration opens at 12:30pm)  
 Location: Sandman Victoria  
 2852 Douglas Street, Victoria ([map](#))  
 Cost: PSBC Member \$15.00 / PSBC Members (Couple/Pair) \$25  
 PSBC Non-Member \$25 / PSBC Non-Member (Couple/Pair) \$45.00  
 Registration: Available soon

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

# Champions FOR PARKINSON'S

- Shifting Gears for Parkinson's: March 13, 2017 – October 31, 2018 ([read more](#))
- Donate a Car: Ongoing ([read more](#))
- Naturally Urban Pet Food Delivery Sales: Ongoing ([read more](#))
- Tea Parky: 35% from every sale on [TeaParky.com](http://TeaParky.com) will go to PSBC, ongoing. *Special: Use promo code PSBC at checkout for 10% off your purchase.*
- Thoughts R Life Apparel: Online apparel sales that benefit PSBC, ongoing ([read more](#))
- Shake, Shake, Shake: May 25, 2018 ([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](mailto:mdzaferovic@parkinson.bc.ca) or 1-800-668-3330.

## NEWS & ANNOUNCEMENTS

### NEW! KAMLOOPS CAREGIVER SUPPORT GROUP

Parkinson Society British Columbia (PSBC) and MS Society of Canada – BC & Yukon division are partnering to offer a special Kamloops Carepartner Support Group. This monthly volunteer-led support group is intended for individuals caring for a loved one with Parkinson's disease or Multiple Sclerosis. If you or someone you know may be interested in joining this group, please contact PSBC at [info@parkinson.bc.ca](mailto:info@parkinson.bc.ca).

### PSBC RESOURCES

Start your New Year off on the right foot! This winter, take some time to refresh your memory and expand your knowledge of Parkinson's disease. We encourage you to review the many helpsheets and resources available at: [www.parkinson.bc.ca/resources](http://www.parkinson.bc.ca/resources).



## GROUPLINK SURVEY

This January we will be sending each support group facilitator paper copies of a GroupLink survey to distribute to support group participants. Think of it as a group activity! Your feedback is extremely valuable and will help us make improvements to the publication in the future. Please take the time to fill out the survey and return it to your facilitator.

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## IN-SERVICE PRESENTATIONS

In-service presentations are public opportunities for individuals to learn more about Parkinson's disease. Presentations are facilitated by PSBC staff or Speaker's Bureau volunteers who provide information on Parkinson's symptoms and treatments. They are held across the province in care facilities, libraries, community centres, etc.

- On January 18th, 2018, a Speaker's Bureau Volunteer will be presenting at St. Michael's Care Facility ([7451 Sussex Avenue, Burnaby](#)) from 11:00am – 12:00pm.
- On January 25th, 2018, Myriame Lépine Lyons will be presenting at the Tommy Douglas Branch of the Burnaby Public Library ([7311 Kingsway, Burnaby](#)) from 6:00pm – 7:30pm.
- January 31st, 2018, Myriame Lépine Lyons and Holy Family healthcare professionals will be presenting at the Holy Family Hospital ([7801 Argyle Street, Vancouver](#)) from 1:00pm – 3:30pm.

Contact Myriame at [mlepinelyons@parkinson.bc.ca](mailto:mlepinelyons@parkinson.bc.ca), 604-662-3240 or 1-800-668-3330 to register for one of these presentations, or to become a Speaker's Bureau volunteer!

**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.

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## TIP JAR

Ever feel like you struggle to express your true emotions? Can't find the right words to describe how you feel? Emotions can be hard to pinpoint, especially when we are feeling them deeply. Using the Mood Meter app (<http://moodmeterapp.com>) you can build emotional intelligence to last a lifetime. For only \$1.39 you can download this app on your smart device and start expanding your emotional vocabulary.

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



## DISCUSSION QUESTIONS

1. What stigmas exist around Parkinson's disease?
2. Have you ever felt ashamed to disclose/describe your condition? If so, why do you think that is/was?
3. Mental health awareness campaigns such as Bell's 'Let's Talk' campaign aim to decrease stigma and increase public awareness. Do you think that campaigns like this are effective? Why or why not?

## STIGMA IN PARKINSON'S DISEASE

Thanks to an increase in awareness campaigns and educational initiatives, there have been some recent prominent public discussions around mental health stigma. However, stigma is not confined to the realm of mental health, and can be especially impactful on individuals with disabilities and neurological disorders. Individuals with Parkinson's disease (PD) are uniquely vulnerable to social stigma, as the disease is often misunderstood by the general population, and, as a symptom of Parkinson's disease they may also experience challenges with mental health.

Erving Goffman defined stigma as "the situation of the individual who is disqualified from full social acceptance" (Goffman, 1963). In a recent review of qualitative studies on stigma and Parkinson's disease, Maffoni et. al. determined that stigma may have a direct impact on quality of life for both people with Parkinson's and their carepartners/caregivers. The study concludes that the stigma people with PD may experience in social settings is as impactful as the various motor and non-motor challenges of Parkinson's disease. "In fact, stigma is not only a feeling of shame and embarrassment arising from a self-perception of inadequacy due to loss of autonomy and visible symptoms, but also an experience related to the attitudes and beliefs of the social context towards the PD patient who is stigmatized and forced to [withdraw]. That is, it is the negative or positive response of the outside world that may do the difference" (Maffoni et. al., 2017). In other words, a social environment where someone feels accepted will have a positive impact on a patient's health and mental well-being. However, even if one does feel accepted and supported, they may internalize stigma. This is why it is important to address stigma in relation to Parkinson's disease.

## ADDRESSING STIGMA

This past October, the American National Alliance on Mental Illness (NAMI) asked their Facebook community how they combatted stigma in their everyday life. Their tips include the following:

- Talk openly
- Educate yourself and others
- Be conscious of language
- Encourage equality between physical and mental illness (or, visible vs. invisible symptoms)
- Show compassion
- Choose empowerment over shame
- Let the media (or others) know when they're stigmatizing
- Don't harbour self-stigma. One Facebook commenter explains, "I fight stigma by not having stigma for myself – not hiding from this world in shame, but being a productive member of society. I volunteer at church, have friends, and I'm a peer mentor and a mom. I take my treatment seriously. I'm purpose driven and want to show others they can live a meaningful life" (NAMI, 2017).



## PARKINSON'S DISEASE AND MENTAL HEALTH

Parkinson's disease is classified as a movement disorder, but in recent years the non-motor symptoms, including changes in mood, have been acknowledged as impactful components of the disease. At least 50% of people with PD experience depression and/or anxiety. People with Parkinson's may also experience apathy, cognition changes and are at an increased risk of developing dementia.

Mood changes in PD, like depression and anxiety, can be caused by the very understandable reaction to your initial diagnosis and changes you experience as the disease progresses. It is normal to be worried about your symptoms and to wonder what is coming in the future. Depression and anxiety can also be caused by changes in your brain chemistry. In addition to decreasing the amount of available dopamine, PD can affect other circuits and neural pathways that control your mood. In many cases, depression and anxiety can appear prior to the onset of physical symptoms of PD. Some people don't know why they have become depressed or anxious, and many look back over the years and realize they developed these symptoms prior to the onset of the motor symptoms, such as tremor or rigidity.

## DIAGNOSIS AND TREATMENT CHALLENGES

The good news is that PD related mental health challenges are treatable, but a number of factors can delay early diagnosis and treatment. Some of these factors include:

- Mental health concerns still have a stigma attached to them. Some people can feel embarrassed about what they are experiencing and think that they should just "get on with it". Other people will deny being depressed or anxious when it is mentioned by other people.
- Many healthcare professionals, including family physicians, are unaware that mood disorders are part of PD. Depression and anxiety may thus go unnoticed and untreated.
- The general public does not understand that these changes are a result of having PD, making the symptoms more difficult to talk about.
- Some of the physical symptoms of PD mimic those of depression. For example, lack of facial expression, fatigue and slowed thinking processes can make a person appear depressed when they are not. As a result, the diagnosis of PD depression can be difficult.

**If you are a person with Parkinson's who experiences burnout, anxiety, unrest and/or depression, PSBC recommends you consider the following resources:**

- Counselling ([learn more](#))
- Support groups ([learn more](#))
- Dealing with Depression and Anxiety helpsheet ([download](#))
- Doctor's Alert! Mood Disturbances in Parkinson's Disease helpsheet ([download](#))
- Apathy helpsheet ([download](#))
- Cognitive Health helpsheet ([download](#))
- Parkinson's and Dementia helpsheet ([download](#))



## CAREPARTNER/CAREGIVER STIGMA

Carepartners/caregivers for people with Parkinson's or other marginalized conditions may experience "stigma by association". One study quoted by the Mental Health Commission of Canada found that carepartners/caregivers may have low self-esteem as a result of stigmatizing behaviour from friends, healthcare providers and the media. Confronting the stigma people with certain illnesses and caregivers face, as well as acknowledging the contributions and sacrifices made by carepartners/caregivers, are important steps in providing adequate social support (Mental Health Commission of Canada, 2017).

### RECOGNIZING THE NEED FOR SELF-CARE

Edie Bijdemast is a retired Science and Biology teacher who is the primary caregiver for her mother Henny, aged 93. Like many others who are diagnosed with Parkinson's disease (PD), the first symptom Henny demonstrated was increased anxiety, which manifested years before she was officially diagnosed with PD. Over time, the anxiety was coupled with depression. At this point, Henny was prescribed medication to help manage these symptoms.

Now, mother and daughter live in the same condo complex. Henny is currently living with advanced Parkinson's; she frequently feels dizzy and nauseous and struggles with bloating as well as hot flashes. Henny sometimes has extreme mood swings, and during these episodes, Edie needs to guide her with breathing exercises to help her calm down. It is very difficult for Henny to leave her apartment now and she requires near-constant care. This has taken a toll on Edie's own mental health. Last spring, Edie began to develop serious anxiety attacks that involved laboured breathing and difficulty processing information. Her doctor diagnosed her with caregiver distress and prescribed medication to help manage her insomnia and shortness of breath. This was a wake-up call to Edie: "It was not until then that I realized I had to take better care of myself if I wanted to be an effective caregiver," she writes in an email interview.

To help alleviate stress, Edie journals, attends yoga, plays with puzzles and enjoys nature walks. Since January 2016, she has also made use of the free, short-term counselling offered by PSBC over the phone. Her counsellor has helped her learn a number of coping strategies to focus on the present rather than worrying about the future. Edie has also found support by participating in a free on-line Mindfulness for Wellbeing and Peak Performance course through [www.FutureLearn.com](http://www.FutureLearn.com). This course provides step-by-step instruction on how to reduce emotional reactivity to difficult experiences. It has provided her with such comfort that she is currently taking it for the third time. Edie has also made arrangements with three different companies for in-home caregiving support in order to obtain some respite time for herself.

In their day-to-day lives, Edie and Henny strive to maintain a positive attitude. Each day, they discuss one or two different photos of treasured moments they shared in their past. Since Edie needs to stay close to home to care for her mother, her retirement travel plans have been placed on hold, so she purchased a 365 day travel calendar which enables her to quench her wanderlust a bit every day. Finally, Henny and Edie also find comfort in humour. Edie writes, "It is said that laughter is the best medicine and, especially during difficult times, we try to look at the funny side of things. Even a small smile every now and then can be so very uplifting."



## RESOURCES FOR CAREPARTNERS/CAREGIVERS

Carepartners/caregivers need support, too! PSBC offers a number of carepartner/caregiver-specific resources and strive to continuously improve our offerings.

- Asking for and Accepting Your Own Support ([read more](#))
- Caring for Someone with Parkinson's ([brochure](#))
- Self-Care for Parkinson's Caregivers (videos) ([Part 1](#)) ([Part 2](#))
- Counselling ([learn more](#))
- Support groups ([learn more](#))
- Never Giving Up (video) ([view](#))
- PDLINK – be matched with fellow a Parkinson's carepartner/caregiver ([learn more](#))
- Coming soon: look out for the new PSBC Carepartner's Guide in 2018

### Sources

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. New York, New York: Simon and Schuster Inc.

Maffoni, M. et. al. (2017). Stigma Experienced by Parkinson's Disease Patients: A Descriptive Review of Qualitative Studies. *Hindawi*. Retrieved from <https://www.hindawi.com/journals/pd/2017/7203259/>

National Alliance on Mental Illness (NAMI). (2017). *9 Ways to Fight Mental Health Stigma*. Retrieved from <https://www.nami.org/Blogs/NAMI-Blog/October-2017/9-Ways-to-Fight-Mental-Health-Stigma>

Mental Health Commission of Canada. (2017). *Caregiving*. Retrieved from <https://www.mentalhealthcommission.ca/English/focus-areas/caregiving>