

Please be advised that Parkinson Society British Columbia's office is closed for the holidays and will be reopening on Tuesday, January 3, 2017.

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 Stacey at sdawes@parkinson.bc.ca or 1-800-668-3330 for more details.

COMMUNICATION AND SWALLOW WORKSHOP - VANCOUVER

This full day workshop will focus on the communication and swallowing challenges faced by people with Parkinson's (PwP). The interactive and participatory format will allow attendees to practice treatment techniques and gain insight from a registered speech-language pathologist. This year, participants will be required to watch a pre-workshop webinar prepared by Sherri Zelazny to introduce the topic of communication and swallowing challenges in Parkinson's. The pre-workshop materials will be sent to you via e-mail upon registration. This workshop is open to those already experiencing communication & swallowing challenges, as well as those who wish to be proactive in their treatment. A catered lunch will be provided.

To ensure the best learning experience, a minimum of 25 participants will be required 7 days prior to the event date. Please be advised that if these numbers are not met, we will be unable to proceed with the workshop and all registrants will receive a full refund.

Date: Friday, January 27, 2017
 Time: 10:00am – 3:00pm
 Location: Broadway Church, Lower Auditorium | 2700 E. Broadway, Vancouver ([map](#))
 Fees: Member \$40.00 | Member (Couple/Pair) \$70.00
 Non-Member \$50.00 | Non-Member (Couple/Pair) \$90.00
 Facilitator: Sherri K. Zelazny, MA RSLP
 Registration: Members: <http://bit.ly/CSMemReg>
 Non-Members: <http://bit.ly/CSNonMemReg>

TIME OUT FOR CAREPARTNERS

PSBC recognizes the efforts made by carepartners and caregivers every day. On February 25th 2017, we hope that carepartners across the province will be able to join us for a day of education, socialization and relaxation. Guest speakers will share experiences and everyday 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 exercising, games, socializing), while their carepartner participates in discussions with other carepartners. We ask that those PwP coming to the February 25th event respect this room divide, and not attend sessions unintended for them. This room will be managed by volunteers; volunteers will not be medical professionals.

Date: Saturday, February 25, 2017
 Time: 10:00am – 2:30pm
 Location: Burnaby Executive Suites | 4201 Lougheed Hwy, Burnaby ([map](#))
 Fees: PSBC Member \$30.00 | PSBC Members (Couple/Pair) \$45.00
 PSBC Non-Member \$40.00 | PSBC Non-Member (Couple/Pair) \$55.00
 Registration: Members: <http://bit.ly/PSBCMemReg>
 Non-Members: <http://bit.ly/PSBCNonMemReg>



**Save
the
Date**



REGIONAL CONFERENCE - KELOWNA

Our next regional conference will take place in Kelowna on Saturday, March 4, 2017.

PROVINCIAL CONFERENCE

Our Provincial Conference will take place on Saturday, June 3, 2017.

More details about both events will be provided in the new year.

Photo and video release: During Parkinson Society British Columbia's (PSBC) events, photographs and video may be taken and subsequently used in PSBC's newsletters or promotional material whether in print, electronic or other media, including PSBC's website.

By participating in PSBC's events, you grant PSBC the right to use your name and photograph for such purposes.

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

Interested in learning more about our 2017 plans? Check out our [2017 at a glance page](#) on our website.

CHAMPIONS FOR PARKINSON'S

- Shake, Shake, Shake!: Friday, January 27, 2017 ([read more](#))
- 4th Annual Chocolate and Beer Tasting: Sunday, March 5, 2017 ([read more](#))
- Cotswolds Walking Holiday: August 31 - September 8, 2017 ([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.

Champions FOR **PARKINSON'S**

AWARE IN CARE KITS

Sales of Aware in Care kits will begin in early January. Other than the cost of shipping, kits will be free to members. Once the kits are available, you may order online at <http://parkinson.bc.ca/awareincare>.

FACILITATOR TELECONFERENCE / WEBINAR

On January 24, 2017, Stacey Dawes, Information and Programs Manager, invites all support group facilitators to join her for a 1 hour meeting at 9:00am via webinar or teleconference. She will be leading a conversation about upcoming PSBC events, support group visits and check-ins, and expectations of support group participants. Support group facilitators will receive an email from Stacey in early January with registration instructions and an agenda outline.

VOLUNTEER

VOLUNTEERING WITH PSBC

PSBC is always looking for dedicated and enthusiastic volunteers. We are currently recruiting:

- **Support Group Facilitators** – A support group facilitator works to create an environment that is safe and respectful, and where participants feel comfortable sharing their experiences, insight and knowledge with others.
- **Speakers Bureau** – Are you a health care professional, teacher or public speaker, active or retired? Would you be interested in spreading awareness to communities about Parkinson's disease? PSBC is looking for individuals who are passionate, educated and experienced with Parkinson's disease who are interested in sharing their knowledge with the public through presentations.

To learn more about becoming a support group facilitator or speakers bureau volunteer, please contact Stacey at sdawes@parkinson.bc.ca or 1-800-668-3330.

NEW! YOPD Online Support Group

Parkinson Society British Columbia is piloting an online support group for those with Young Onset Parkinson's disease facilitated by Myriame Lépine Lyons.

Date: 2nd Tuesday of each month
Time: 7:00pm - 8:00pm
Location: Online. A valid internet connection will be required to participate.
Registration: You must register to attend this support group by contacting Myriame at mlepinelyons@parkinson.bc.ca or 1-800-668-3330

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! <http://www.parkinson.bc.ca/exercise>

Note: Any listing in the aforementioned documentation 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.

SUBSCRIBE TO GROUPLINK!

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

TIP JAR

Do you have any tips or tricks that you would like to share with your 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 Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330.



DISCUSSION TOPIC

MANAGING FATIGUE

Discussion questions:

1. What times of the day are you most affected by spells of fatigue?
2. What are some strategies that you use to help manage this Parkinson's symptom?
3. Who have you spoken to about your fatigue?

Do you or a loved one with Parkinson's disease (PD) feel physically or mentally exhausted? This could be fatigue – a feeling of deep tiredness that has no apparent explanation and does not improve with rest. About half of people with Parkinson's disease report that fatigue is a major problem, and a third say it is their single most disabling symptom. Although many of us use the terms fatigue and sleepiness interchangeably, they are considered to be separate challenges. Sleepy people may fall asleep at abnormal times during the day; whereas people with fatigue need to rest but do not generally drop off to sleep.

What is fatigue in Parkinson's?

Fatigue has been described as an overwhelming sense of tiredness, a lack of energy and a feeling of exhaustion. This can be a physical, mental or an emotional feeling. Anybody can feel fatigued when they are working too hard, or when pressures at work or home cause stress. Fatigue can also be a symptom of an illness, like Parkinson's disease (PD). At this time, no specific mechanism has been shown to cause fatigue in PD. Sometimes it can be difficult to determine what may be causing it. Talk to your doctor or neurologist if you are experiencing fatigue so they can help you decipher its cause.



For some people, fatigue can be very difficult to live with, while others can manage the symptom well. What's more is that people who are newly diagnosed with PD can be just as likely to experience fatigue as those who have had the condition for some time – in fact, it may be one of the earliest symptoms you experience.

Can fatigue be exacerbated by sleep disturbances?

Yes. Many people with Parkinson's can experience problems with sleeping at night, which can often leave you feeling tired and lethargic during the day. You may wake up during the night because of tremor or stiffness, or because you are having difficulty turning over in bed. You may also be waking up in the night because you need to go to the bathroom.

If you are having any of these problems, you may not feel very well rested in the morning, and could experience difficulty with completing tasks throughout the day. While night-time problems can contribute to excessive daytime sleepiness, frequent napping during the day can also make sleeping at night more difficult.

It is important that you find the reasons for sleep and night-time problems, because many of these can be treated and may help you feel better during the day. You could try to develop good sleeping habits by having a regular bedtime and sleeping hours. Relaxing before you go to bed, by doing things like taking a warm bath, can also help. Stimulants such as alcohol, tobacco and caffeine should be avoided in the evenings. For more information about sleep disturbances, [read our helpsheet](#).

What can I do about fatigue?

Some of the main causes of fatigue, such as sleep disturbance, depression or Parkinson's symptoms, can be treated medically. But there are a number of things you can do yourself to try to avoid fatigue or help minimize it.

Work with your healthcare professional

To get help, a complete health history and physical exam is first necessary to rule out non-Parkinson causes. Sometimes problems not associated with PD, such as anemia, may be found. If you are experiencing fatigue, ask yourself the following questions and record them in a notebook. Then, bring this information to your next doctor's appointment and share it with your doctor:

- When do I feel fatigued?
- How long do my feelings of fatigue last each day?
- Does my fatigue fluctuate with my symptoms?
- Does my fatigue fluctuate with the time that I take my medications?
- On a scale of one to ten, how fatigued am I in the morning, around noon and in the afternoon?

The answers to these questions can help you and your doctor work together to identify possible causes of the fatigue you are experiencing. If necessary, Parkinson's medications can be adjusted.

At work

If you are still working, it may not be easy to rearrange your daily tasks. Instead, try to take regular, short breaks. This can help you work better and avoid fatigue building up. A break can be something as simple as making a cup of tea, having a chat with a colleague or sitting back for a few moments with your eyes closed. For information about disclosing your disability to employers [see our helpsheet](#).

Around the home

If you live with someone, it may be useful to divide household tasks, so that you do the jobs you can manage more easily. If you live alone, it may be helpful to hire someone or ask a friend to help with cleaning or preparing meals. For more information about living independently [see our helpsheet](#).

Exercise

While this may seem like a broken record, exercise is an important tool to manage Parkinson's symptoms. Try to get regular exercise throughout your week. This may seem difficult at first, but your stamina will build up over time. For more information about physical activity and Parkinson's [read our helpsheet](#). Mental exercise is also important, so try and stay involved with any hobbies and interests. If you have time during the day, try to do a variety of activities, as boredom can also lead to fatigue.

Diet

Eating a healthy, balanced diet is important, so try to make sure you are eating the right foods. Watch Dr. Laurie Mischley's nutrition presentation to find out more about what you should and shouldn't eat (<http://bit.ly/Nutrition-PD>), or you can read more about nutrition in our [helpsheet](#). Some people find that a small snack every couple of hours provides them with a constant supply of glucose, which is used for energy. It is also important to try to avoid constipation (when stools are hard and difficult to pass), as this can make you feel sluggish. Read through our [Bowel Management Program helpsheet](#) to find out ways you can reduce constipation.

Daily routine

Occasionally, you may feel fatigued after a large midday meal. A short nap may be particularly helpful at this time and may reduce the sense of fatigue. You could also try having a smaller, lighter meal at lunchtimes

Above all, know your limitations. Try to perform as much of your daily routine as you can by yourself, but take a rest or get help when you think you need it. If you are feeling fatigued, it may not help to try to force too much into one time period. You may find that even after a good night's rest you are feeling more tired and less energetic than usual. This could be due to having overworked the day before, or due to the way your condition fluctuates. Whatever the cause, keep in mind that you will have days when you feel tired and days when you feel better than usual.

Sources:

National Parkinson Foundation. (n.d.) *Fatigue and Parkinson's Disease*. Retrieved from <http://www.parkinson.org/sites/default/files/fatigue-and-parkinsons.pdf>

Parkinson's UK. (January 2014). *Fatigue and Parkinson's*. Retrieved from https://www.parkinsons.org.uk/sites/default/files/publications/download/english/fs72_fatigueandparkinsons.pdf



TIPS TO HELP MOTIVATE YOURSELF AND YOUR PARTNER

Sustaining motivation can be tough under the best of circumstances. How can you stay motivated when your to-do list is overdue, you or your partner have an unexpected visit to the dentist, your driveway needs salting and you can't find time in the day for yourself?

Similar to exercise, motivation takes effort and practice. Most of us can't just get up in the morning and ride 50km on our bikes. We need to train and set goals in order to achieve this 50km ride. Motivation is not given to us; we have to go and get it!

Here are 4 steps to cultivating motivation:

1. **Define a goal.** It is important to see it, feel it and hear the sounds that accompany the end result (wind rushing through your hair, applause, your partner's smile).
2. **Write out each step to your goal.** This may sound trivial however when we write out a plan of action, we are more likely to reach the end. Plan out how you or your partner will achieve the defined goal. Suggest small steps or breakdown the task (e.g., Step 1 – Get out of bed. Step 2 – Bathe. Step 3 – Dress. Step 4 – Eat Breakfast. Step 5 – Read the paper.). It's important to visualise each step.
3. **Make a list of the reasons you want to accomplish the goal.** Listing the reasons for a goal can help highlight the rewards that come with accomplishing a goal. For instance, if your goal is to take a walk after breakfast, than thinking about the reward of feeling energized and refreshed after the walk would be a reward or a reason to accomplish the goal.
4. **Start slowly and make the steps attainable.** It's easy enough to define your goal. However, when the time comes to taking the first step, we sometimes get overwhelmed thinking about the end goal. Reminding yourself of the steps you laid out and completing them chronologically helps us stay grounded and focused. Tread slowly. Take your time. It's not a race.

The above steps are ways of cultivating motivation in a linear fashion. There are many other ways individuals motivate themselves to get a task done, complete an exercise regimen or take medication on time. Here are some others ways that may work for you:

- **Set rewards.** Rewards are an important part of creating new habits. If motivation is harder to come by, you may want to identify a tangible reward for your completing your goal. For instance, if your goal is to take out the garbage you may want to imagine the feeling of watching your favorite TV show (reward) after taking out the garbage (goal) to motivate you.
- **Make a deal with your family and friends.** Accountability to others can be a strong motivator for individuals. By making your goal public you are letting others know about your intentions. They may even help you complete the goal by offering reminders or tricks to complete the goal.
- **Reflect on your successes.** Looking back at your efforts and successes can be extremely motivating when feeling stuck. There are bound to be times in your life when you've completed a goal you didn't think was possible. Reflect on these and bring those emotions with you in your attempts to complete the goal ahead.
- **Cultivate self-compassion.** There will be times when we will think negatively, especially when some things are much harder to complete than they used to be. The changes that happen in our lives must be met with flexibility and understanding. For people affected by Parkinson's it is important to remember that it isn't your fault! Think of a child who stumbles off a sidewalk, would you become angry and frustrated with them? No. You would help them get back up and ask if they are okay. It is compassion and empathy that fills your heart for this child. Do the same for you and be kind to yourself!

TIP: During the winter months, both you and your loved one may be susceptible to decreased energy and seasonal depression. [National Parkinson Foundation](#) has some useful tips to help avoid seasonal depression, such as continuing your regular exercise routine and keeping up with social engagements. You can read more about Seasonal Affective Disorder (SAD) on the [Mayo Clinic's website](#). If you think you or a loved one may be experiencing symptoms, please ensure that a physician is consulted.