

## UPCOMING EVENTS

- **Step Up, Stretch Out: April's Accessible Self-Directed Exercise Challenge** | April 1-30, self-directed  
Learn more & register: <https://bit.ly/stepupstretchout-23>
- **New Approaches to Daily Activities Applying the Alexander Technique** | Tuesdays, April 4, 11, 18, 25  
Learn more & join waitlist: <https://bit.ly/AlexanderTechniquewaitlist>
- **Rock Steady Boxing with Doug** | Tuesdays, April 4, 11, 18, 25, May 2, 9, 16, 23, 30  
Learn more & register: <https://bit.ly/rocksteady2-23>
- **Improv for Parkinson's: Laughter is the Best Medicine** | Wednesday, April 5  
Learn more & register: <https://bit.ly/laughterimprov-23>
- **DOPABEATS with Doug Pickard** | Wednesdays, April 5, 12, 19, 26 & May 3, 10  
Learn more & register: <https://bit.ly/dopa2-23>
- **Dancing with Parkinson's** | Wednesdays, April 5, 12, 19, 26  
Learn more & register: <https://bit.ly/dancewithPD-23>
- **SongShine with Joani** | Thursdays, April 6, 13, 20, 27, & May 4, 11, 18  
Learn more & register: <https://bit.ly/songshine2-23>
- **April Challenger** | Thursdays, April 6, 13, 20, 27  
Learn more & register: <https://bit.ly/AprChallengerReg-23>
- **Annual General Meeting** | April 22  
Learn more & register: <https://bit.ly/agmreg22-23>
- **Victoria Regional Conference (In-Person)** | April 29  
Learn more & register: <https://bit.ly/VicConf-23>
- **Virtual Open House** | May 2, 2023  
Learn more & register: <https://bit.ly/OpenHouseReg-23>

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## UPCOMING FUNDRAISING EVENTS

### *Champions for Parkinson's*

- Donate a Car Canada: Ongoing (read more: <http://bit.ly/2ORTuJn>)

*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 disease (PD)? Become a Champion for Parkinson's and plan your own independent community fundraising event! Contact us at [events@parkinson.bc.ca](mailto:events@parkinson.bc.ca) or 1-800-668-3330.

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### TIP JAR

The Tip Jar is where we share advice from Parkinson's community members on a wide range of topics from daily lifestyle hacks to safety. This month we share a tip on bowel care!

Many folks with Parkinson's experience chronic constipation. A member from the Trail/Castlegar Support Group found that placing a small toilet footstool around the base of the toilet and propping your feet onto the stool when passing a bowel movement helps reduce strain on the colon.

*Do you have any tips or tricks that you would like to share with the Parkinson's 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 at [info@parkinson.bc.ca](mailto:info@parkinson.bc.ca).*

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### NEWS & ANNOUNCEMENTS

#### **April is Parkinson's Awareness Month**

Every year, Parkinson Society British Columbia (PSBC) dedicates the month of April to raising awareness of the unique experiences of people with Parkinson's, and the needs of our community. Parkinson's Awareness Month is an opportunity to engage the public in expanding their understanding of Parkinson's, and the profound effects it has on the lives of over 15,000 British Columbians living with the disease. This April, we want to spread the message that *Parkinson's is **more than a tremor***. The disease can affect all aspects of one's life, and there is currently no known cure.

Our 2023 campaign highlights:

- **Personal journeys** shared by people with Parkinson's, their families, and carepartners.

- The importance of **living well with Parkinson's**, through self-management, self-reliance, and self-advocacy.
- **Community ties and peer support** bringing together the Parkinson's community across British Columbia.

We invite you to take part in our awareness campaign by submitting content that shares your story, your way. We are looking for writing pieces (i.e.: poems, short stories), artwork (i.e.: paintings, photography), videos, and written interviews. [[learn more](#)]

### ***Above and Beyond Award Nominations now open***

Consider nominating a member of the Parkinson's community who embraces the "Above and Beyond" philosophy in their life. Nominations will be accepted through Thursday, April 6 with the awards presented at the April 22 Annual General Meeting. [[learn more](#)]

### ***Register now for our Annual General Meeting (AGM) 2022***

We invite you to join us for our AGM on Saturday, April 22, 2023, featuring guest speaker, Dr. Silke Appel-Cresswell! Dr. Silke Appel-Cresswell is a movement disorder neurologist, an associate professor (grant tenure) for Medicine/Neurology at the University of British Columbia (UBC) and holds the Marg Meikle Professorship for Research in Parkinson's disease (PD). Symptoms of mild, moderate, and advanced cognitive impairment will be discussed, as well as research on the impact of lifestyle interventions that may prevent or offset cognitive impairment in Parkinson's. In exploring the efficacy of lifestyle interventions, she will also discuss the extent to which evidence is validated for cognitive training, neuro-protective and neuro-degenerative delay, diets, and exercise.

**Register today** at <http://www.parkinson.bc.ca/agm22>

Our 2022 Annual Report and financial statements will be available on our website shortly.

***Please be advised this is member-only virtual event.*** Non-members interested in attending must pay the \$25 membership fee at [www.parkinson.bc.ca/membership](http://www.parkinson.bc.ca/membership), or by contacting Susan Atkinson, *Donor & Member Services Coordinator*, at [satkinson@parkinson.bc.ca](mailto:satkinson@parkinson.bc.ca) or 1-800-668-3330 ext. 263.

***PD Link volunteers wanted***

Interested in mentoring and giving back within the Parkinson's community? PDLink is a peer-to-peer support program for people with PD and their carepartners. We are seeking volunteers who are carepartners, or have had PD for several years, who would like to mentor others about Parkinson's. To learn more about the program, visit the [PDLink webpage](#). If interested, contact Liz Janze at [ljanze@parkinson.bc.ca](mailto:ljanze@parkinson.bc.ca).

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***DISCUSSION TOPIC: April Awareness Month: Self Advocacy******Discussion Questions***

1. What are some ways we can collectively reduce stigma faced by People with Parkinson's (PwP)?
2. What are some ways you practice self-compassion?
3. This April Awareness Month, what are some ways you can advocate for yourself and your community?

Parkinson's disease (PD) can affect an individual's quality of life by causing a range of motor and non-motor symptoms. Many people with PD find it challenging to communicate their needs and concerns to healthcare providers, caregivers, or family members, leading to frustration, anxiety, and a reduced sense of control over their PD management.

***What is Self-Advocacy?***

Self-advocacy involves taking an active role in decision-making related to one's health and well-being. For people with PD, self-advocacy skills are crucial to effectively communicate their needs and preferences, access the most helpful healthcare services, and make informed decisions about their treatment and care. These skills can lead to better outcomes and improved quality of life.

According to a study in the Journal of Parkinson's Disease, self-advocacy training programs led to significant improvement in participants' sense of control over the management of their PD symptoms, resulting in a reduction of anxiety and depression symptoms. Additionally, self-

advocacy skills can help PwP feel more confident and assertive in their interactions with healthcare providers, which increases their adherence to treatment plans, physical activity, and healthy lifestyle habits.

According to [Understood](#), there are three key elements in self-advocacy:

1. Understanding your needs
2. Knowing what kind of support might help you
3. Communicating your needs to others

To better understand your needs, it is recommended that the individual with PD and/or their carepartner/caregiver participate in educational events and review other available resources. This will help determine what kind of support may help by staying up-to-date on available medications and therapies. It can also be helpful to rely on a well-informed Parkinson's peer or mentor to ask for tips, recommendations, or discuss symptoms.

### **Practicing Self-Advocacy**

When PwP speak up for themselves and challenge negative attitudes and stereotypes, they can increase awareness and understanding of the disease to help reduce stigma. You may find these tips helpful for practicing self-advocacy:

1. **Educate yourself:** Knowledge is power. The more you understand about Parkinson's, the more equipped you will be to help others understand, and to challenge the stigmas that can influence your own beliefs.
2. **Challenge yourself and educate others:** Use your self-education to be compassionate towards those who may pass judgement due to limited knowledge of Parkinson's. When you feel comfortable, you can share your own Parkinson's story to help break down stereotypes and reduce stigma.
3. **Advocate for your community:** Finding an understanding and compassionate community of people with Parkinson's can comfort those on their journey with combatting stigma and self-acceptance. The collective voice of a passionate community

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can also challenge policies and laws that perpetuate institutional stigma and discrimination.

Self-advocacy is an important skill that improves with practice. It does not come naturally or easily for everyone, especially for those who have had negative experiences in the past contributing to a lack of trust in their communities and healthcare (Hanson, 2022). It is also a challenge for minority groups such as women, people of colour, and those whose native language is not English. In these instances, it becomes even more essential to practice self-compassion and rely on your loved ones for support.

Overall, self-advocacy is crucial in creating a healthy Parkinson's community and an effective tool to tackle stigma. When PwP practice self-advocacy, they are more likely to receive better care and feel more agency in their lives.

### *Stigma and Parkinson's*

Stigmatization involves identifying and marking an undesirable characteristic in a way that narrows a person's social identity to that characteristic. The consequences of stigmatization include marginalization and, in some cases, dehumanization. [It also] often contributes to poor global health outcomes [...]" (Chen & Cartwright, 2016). People with Parkinson's are vulnerable to stigma due to the visible nature of some symptoms and a lack of public awareness of the disease. Research has demonstrated that PwP may experience stigma in various ways, including discrimination in the workplace, social rejection, and negative attitudes from healthcare providers. This can lead to internalizing feelings of shame and self-blame, further hindering self-advocacy, the expression of needs, and engagement in appropriate treatment. (Eccles, et al., 2022). Recognizing stigma and how it can impact mental health, is the first step towards self-compassion and self-acceptance. In reducing internalized stigma, PwP can better position themselves to self-advocate while simultaneously working to break down public misconceptions.

### *Self-Compassion*

Self-compassion is defined as non-judgemental acknowledgement of one's own experiences, with an emphasis on kindness, concern, and support. It is an important way to regulate emotions, boost wellbeing, and self-soothe. Individuals with higher self-compassion may be able to assess interactions more objectively with others, as well as positively reframe situations in which they experience stigma, which can reduce distress and increase feelings of safety. PwP with higher self-compassion are also found to internalize negative stereotypes about themselves less frequently (Eccles, et al., 2022).

### **3 Ways to Practice Self-Compassion**

**Practice mindfulness:** Even a quick exercise, such as meditating for a few minutes, can be a great way to nurture and accept oneself while experiencing any pain.

**Comfort your body:** Eat something healthy. Lie down and rest. Anything you can do to improve how you feel physically gives you a dose of self-compassion.

**Be kind to yourself:** Consider how you would offer support to a close friend who is facing a difficult or stressful situation. Then, direct the same kind of responses to encourage yourself (Harvard Health, 2019).

### *Additional Resources*

- Talking to Your Healthcare Professionals [[helpsheet](#)]
- Mindful Moments [[view video](#)]

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*Works Cited*

- “4 Ways to Boost Your Self-Compassion - Harvard Health.” *Harvard Health*, Harvard Health Publishing, 2019, [www.health.harvard.edu/mental-health/4-ways-to-boost-your-self-compassion](http://www.health.harvard.edu/mental-health/4-ways-to-boost-your-self-compassion).
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- Eccles, Fiona J. R., et al. “Stigma, Self-Compassion, and Psychological Distress among People with Parkinson’s.” *Disability and Rehabilitation*, vol. 45, no. 3, Feb. 2022, pp. 425–33, doi:<https://doi.org/10.1080/09638288.2022.2037743>.
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- “Stigma.” *Parkinson Canada*, Merz Therapeutics, [www.parkinson.ca/about-parkinsons/stigma/](http://www.parkinson.ca/about-parkinsons/stigma/). Accessed 22 Mar. 2023.