

UPCOMING EVENTS

- **Move with Confidence: Parkinson's Fitness** | Tuesdays, December 5, 12 & 19
Learn more & register: <https://www.parkinson.bc.ca/movewconf-dec23>
- **Debriefing the Caregiver Role** | Thursday, December 7
Learn more & register: <https://www.parkinson.bc.ca/debriefdec-23>
- **SongShine with Joani** | Thursdays, December 7 & 14
Learn more & register: <https://www.parkinson.bc.ca/songshinenovdec-23>
- **Holiday Stress Management** | Friday, December 8
Learn more & register: <https://www.parkinson.bc.ca/songshinenovdec-23>
- **Holiday Caroling** | Tuesday, December 12
Learn more & register: <https://parkinson.bc.ca/holidaystressmanagement-dec23>
- **Bollywood Dance** | Thursdays, January 11, 18, 25 & February 1
Learn more & register: <https://www.parkinson.bc.ca/bollywoodjan-23>
- **Virtual Open House** | Wednesday, January 24
Learn more & register: <https://www.parkinson.bc.ca/openhouse-24>
- **Move with Martial Arts: Karate Fundamentals** | Tuesdays, February 6, 13, 20 & 27
Learn more & register: <https://www.parkinson.bc.ca/martialartsfeb-23>

UPCOMING FUNDRAISING EVENTS

Donate a Car Canada

[Donate a Car Canada](#) accepts vehicle donations for Parkinson Society British Columbia (PSBC)! Free towing is provided in most areas across Canada. When you donate your car, truck, RV, boat, or motorcycle to PSBC through Donate A Car Canada, it will either be recycled or sold at auction (depending on its condition, age, and location). After your vehicle donation is complete, PSBC will send you a tax receipt and will put your gift to good use.

Brighten the day with a bouquet from Callia Flowers

For a limited time, [Callia Flowers](#) is offering Parkinson Society BC's (PSBC) community members a \$5 discount on any order they place using the code: **PARKINSONBC**. With every order placed using the custom code, Callia will donate 10% of the net sales to the Society. Join

us in making a meaningful impact in our community and spread the love with Callia Flowers today!

We are looking for more Champions!

Do you want to help fund research, grow support networks, and improve the 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 or 1-800-668-3330.

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 educating yourself!

Embrace the power of education by delving into resources, attending webinars, and connecting with others living with Parkinson's disease. Being informed about the condition equips you to navigate its challenges more effectively. Seek out books, articles, and webinars that cover various aspects of Parkinson's—from symptom management to lifestyle adjustments. Engaging with a supportive community of individuals who share their experiences can provide invaluable insights and practical tips. Ask questions, share experiences, and remain open to new information as knowledge can be a powerful tool in managing Parkinson's and enhancing your quality of life.

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.

NEWS & ANNOUNCEMENTS

International Volunteer Day

International Volunteer Day recognized on December 5 acknowledges the invaluable contributions of volunteers worldwide. At Parkinson Society British Columbia, we are deeply appreciative of the role that volunteers play in the delivery of our programs and services. We

recognize their dedication and passion in supporting our mission throughout the year. As we commemorate International Volunteer Day, we want to extend our gratitude to our volunteers and reaffirm our commitment to provide ongoing opportunities for individuals to make a meaningful impact in our communities. The Society offers a range of volunteering opportunities which can be found on our website. [[learn more](#)]

Office Closure

Please note that Parkinson Society British Columbia (PSBC) will be closed for the holidays, December 25, 2023 – January 1, 2024. We will resume operations on January 2, 2024, with our regular hours, 8:30am – 4:30pm. PSBC staff would like to wish you and your family a happy holiday season! [[learn more](#)]

Seeking Support Group Facilitators

Parkinson Society British Columbia is currently seeking volunteer support group facilitators for Abbotsford (in-person), Tri-Cities/Coquitlam Caregivers (in-person), and West Kelowna (in-person). If you're interested in starting your own support group in your area, please don't hesitate to [contact us](#). [[learn more](#)]

Join PSBC's Book Club!

PSBC's Book Club is a social club for like-minded people who have PD, or carepartners of those with PD, to meet and discuss books that are selected by the peer committee or group members. The group meets at 11:30 am on the first Thursday of each month. If you are interested in joining this virtual, peer-led book club, please contact [Kelly Felgenhauer](#).

DISCUSSION TOPIC: Advocacy

Discussion Questions

1. From systemic to self and group advocacy, which form of advocacy resonates with you the most and why?
2. In what ways do you think advocacy has positively impacted the Parkinson's community or your personal journey with Parkinson's?

3. What are some practical strategies you've used to engage in advocacy, such as speaking up, sharing your story, or engaging with healthcare providers?
4. How can we create a safe and supportive environment to encourage individuals to share their stories, and what methods have you found effective in overcoming the barriers of stigma within the community?

Advocacy plays a pivotal role in driving change and delivering essential support for individuals with Parkinson's and their caregivers. An advocate, by definition, is someone who openly champions or supports a particular cause or policy. Advocacy encompasses a range of efforts aiming to influence various facets of society, ensuring a comprehensive approach to address the needs of those affected. Beyond supporting individuals affected by the disease, it also seeks to transform larger systems, policies, and procedures that impact their lives (Fight Parkinson's, n.d.).

Types of Advocacies

Systemic Advocacy

Advocacy operates across different levels, involving *systemic, group, and individual* efforts, all working toward distinct yet interconnected goals (Fight Parkinson's, n.d.). Systemic advocacy strives to influence and reform structural elements that may impede access to quality healthcare, and support services, or hinder societal understanding among individuals affected by Parkinson's disease. It seeks to change government systems, such as laws, policies, representation, and spending, necessitating networking and alliances with decision-makers. This type of advocacy often involves direct communication with policymakers and authorities at municipal, provincial, or federal levels (Hanson, 2022c).

Parkinson Society BC is actively involved in systemic advocacy, exemplified through various campaigns. One notable initiative was our effort to improve access to Duodopa. Our advocacy efforts also extended to enhancing accessibility to Deep Brain Stimulation (DBS) surgery. We have successfully advocated for the doubling of the number of surgeries and the recent recruitment of a second DBS neurosurgeon. As well, we established funding partnerships with

Interior, Island, and Vancouver Coastal Health Authorities to facilitate team-based care for individuals with Parkinson's.

Currently, we are working on a second funding partnership with Island Health Authority. This initiative aims to provide a speech pathologist for Nanaimo and Central Island. We are also working to establish a visiting clinic for the Northern Health Authority, addressing a critical need in this area. Through these strategic partnerships and ongoing efforts, Parkinson Society BC continues to advocate for reducing systemic barriers to comprehensive care for individuals affected by Parkinson's disease.

Self-Advocacy

Self-advocacy is often the initial experience of advocacy for an individual with Parkinson's. It focuses on empowering those living with Parkinson's, along with their families and caregivers, by cultivating essential skills and self-confidence to express their needs and challenges (Hanson, 2022a). This personal development enables individuals to effectively represent their own interests within their communities. This can be through the form of tracking and sharing symptoms with your healthcare teams or attending educational webinars.

Group Advocacy

Group advocacy aims to foster and endorse community organizations representing the collective interests of those impacted by Parkinson's or their families and caregivers. By uniting and voicing concerns as a collective force, these groups become influential advocates for change, addressing common issues experienced by a broader Parkinson's community. It's important to note that group advocacy can also manifest individually, whether by helping a loved one prepare for a doctor's appointment or encouraging others to share their stories. Advocating for others extends beyond formal roles and refers to actively supporting the wellness of others and overcoming barriers to quality care (Hanson, 2022b).

Each type of advocacy plays a crucial role in promoting positive change for individuals affected by Parkinson's. Engaging in any of these advocacy types contributes to a more inclusive, supportive, and understanding environment for those living with Parkinson's disease and their caregivers.

The Importance of Advocacy

Advocacy entails actively speaking up, raising awareness, and taking action to bring about change. In the context of Parkinson's, advocacy spans various crucial aspects:

- **Access to Care:** Advocating for better access to specialized healthcare services, such as neurologists, physical therapists, speech-language pathologists, and occupational therapists, is essential for optimal management of the disease.
- **Research and Innovation:** Encouraging and promoting research initiatives for new treatments, therapies, and technologies is vital to improve outcomes and quality of life for those with Parkinson's.
- **Education and Awareness:** Advocacy plays a significant role in dispelling misconceptions and cultivating a better understanding of Parkinson's within the general public. This aids in reducing stigma and strengthening support networks for the Parkinson's community.
- **Policy and Legislation:** Influencing policies and legislation helps ensure that people with Parkinson's have the necessary support, including access to disability benefits and workplace accommodations.

Getting Involved

Advocacy efforts within the Parkinson's community include various accessible and manageable ways for both individuals with Parkinson's and their caregivers to participate without feeling overwhelmed. Whether through signing petitions, participating in local awareness campaigns, or communicating with elected representatives, every person has the potential to influence and generate significant change. The collective impact of these individual contributions creates a

force capable of driving positive advancements in healthcare, policy, and societal perceptions (Cohen et al., 2006). Here are specific areas in which to engage for effective advocacy:

- **Education is Empowerment:** Knowledge is power. Understanding Parkinson's and its management options is a crucial foundation for effective advocacy. Reliable resources, such as those provided by Parkinson's foundations, research institutions, and healthcare providers, can offer a wealth of information. Learning about Parkinson's better equips you to communicate your needs and what kind of support you require.
- **Building Support Networks:** Effective advocacy is strengthened with allies. Joining support groups and connecting with individuals who comprehend the challenges of Parkinson's can provide essential emotional support and opportunities to learn from shared experiences. It's important to note that being a good advocate doesn't require shouldering the burden alone.
- **Speaking Up and Sharing Personal Experiences:** Participation in community events or sharing personal stories through blogs or social media can raise awareness and cultivate empathy, fostering understanding and support. Effective communication is vital, ensuring your message is clear and concise to convey your needs accurately. Equally important is active listening, which facilitates the building of relationships and learning valuable information.
- **Engaging with Healthcare Providers:** Establishing open and honest communication with healthcare professionals is essential. Being an active participant in treatment discussions, asking questions, and discussing concerns can lead to more personalized and effective care (The New Brunswick Association for Community Living, 2018).
- **Involvement in Research and Clinical Trials:** Participation in research studies and clinical trials can contribute to advancements in Parkinson's treatment. Always discuss these options with healthcare providers to make informed decisions.

Navigating Challenges

While advocacy is essential, it's not without its challenges. Individuals with Parkinson's and their caregivers may encounter various hurdles, including:

- **Emotional and Physical Strain:** The management of Parkinson's, alongside the additional demands of advocacy efforts, can amplify the challenges already present due to symptoms and their daily impact. Living with Parkinson's can often feel all-consuming, resembling a full-time commitment. Balancing advocacy with personal health requires recognizing the importance of self-care. Prioritizing mental and physical well-being is essential to maintain effective advocacy while maintaining a healthy balance.
- **Overcoming Stigma:** The fear of judgment or misunderstanding can silence those affected by Parkinson's, inhibiting their engagement in advocacy. Encouraging openness requires patience, understanding, and the creation of a safe and non-judgmental environment. Breaking down these barriers of stigma gradually empowers individuals to share their stories, enhancing advocacy and understanding of Parkinson's disease.
- **Navigating Healthcare Systems:** Understanding complex healthcare systems and policies can be overwhelming. Seeking guidance from Parkinson Society BC's Healthcare Navigation Services, patient advocacy organizations, and/or social workers can be beneficial. Ensure to ask questions if something is not clear to you. Preparing the questions, you want to ask before a conversation or meeting can help. If you are not comfortable with certain decisions, seek a second opinion and maintain copies of all your medical records.
- **Sustaining Momentum:** Maintaining momentum in advocacy efforts requires determination and perseverance. Some situations may be more difficult, requiring sustained effort over weeks, months, or even years to effect change. Celebrate small victories and stay motivated by focusing on the positive impact of advocacy.

The need for advocating for Parkinson's disease remains ongoing. There are numerous avenues to becoming an advocate, and it's essential to take the time to explore various options to find what best aligns with your abilities and interests. Discover ways to enhance advocacy in your current life, whether for yourself, someone else, or within your community. Although the prospect might seem overwhelming initially, embracing the role of an advocate can be immensely fulfilling and empowering (Cohen et al., 2006). By advocating for yourself and others,

you contribute to fostering understanding, support, and positive change. Remember, every small effort towards advocacy is a step in the right direction.

Additional Resources

Advocacy | Parkinson Society British Columbia [[learn more](#)]

References

- Cohen, L. J., Comstock, A. L., & Kirby, B. J. (2006). Advocacy and the Parkinson's disease community: a true triumph of the spirit. In M. Menza & L. Marsh (Eds.), *Psychiatric Issues in Parkinson's Disease: A Practical Guide* (pp. 297–304). Taylor and Francis.
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- Hanson, J. (2022a, April 8). *Practicing Parkinson's Self-Advocacy*. Davis Phinney Foundation. <https://davisphinneyfoundation.org/how-you-can-be-a-parkinsons-advocate/>
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