

UPCOMING EVENTS

- **Victoria Regional Conference** | Saturday, May 4
Learn more & register: <https://www.parkinson.bc.ca/victoriaregional24>
- **Seated Exercise Circuit** | Thursdays, May 9, 16, 23 & 30
Learn more & register: <https://www.parkinson.bc.ca/seatedexercise24>
- **SongShine with Joani (Series 3)** | Thursdays, May 9, 16, 23, 30, and June 6 & 13
Learn more & register: <https://www.parkinson.bc.ca/songshinemay-24>
- **Deep Brain Stimulation and Non-Motor Symptoms** | Thursday, May 30
Learn more & register: <https://www.parkinson.bc.ca/dbs-24>
- **Move with Shelly** | Tuesdays, June 4, 11, & 18
Learn more & register: <https://www.parkinson.bc.ca/movewshelly-june24>
- **Coffee Connect** | Mondays
Learn more & register: <https://www.parkinson.bc.ca/coffeeconnect>

For a full list of our upcoming events, visit www.parkinson.bc.ca/education-events/

UPCOMING FUNDRAISING EVENTS

Full Throttle

Don't miss the 8th annual Full Throttle motorcycle and car ride starting at Lumbermen's Arch Parking Lot in Stanley Park on Sunday, May 26. Show off your wheels at the Show & Shine, featuring a display of cars and motorcycles, and enjoy an optional drive along the scenic Sea-to-Sky highway to Squamish. Join us on this journey fueled by passion and unity, supporting Parkinson Society British Columbia's programs, services, advocacy, and research for 17,500 British Columbians living with Parkinson's disease. [\[learn more\]](#)

Silent Auction

Join us for our silent auction event dedicated to raising vital funds and support for individuals and families affected by Parkinson's disease. Bid on a diverse range of items and experiences to contribute to our cause while enjoying the excitement of the auction. Your involvement will advance research, raise awareness, and foster a sense of togetherness in fighting Parkinson's.

[\[learn more\]](#)

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.

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 about getting dressed:

If you struggle with putting on socks due to stiffness or dexterity issues, consider trying socks made from bamboo fibre. These socks are silky and smooth, making them easy to slip on without much effort. They are widely available and are reasonably priced. This simple change can make getting dressed in the morning much easier and more comfortable.

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**May is Caregiver Month**

Caregiver Month is an opportunity to honour and appreciate all caregivers who provide essential care for their loved ones with Parkinson's. Caregivers play a critical role in the management of PD, assisting with daily tasks, medication management, and emotional support. Parkinson

Society BC is dedicated to raising awareness of the challenges faced by caregivers, as well as providing resources and support to help them in their role.

Welcoming Dr. Joanne Baker, PhD as Chief Executive Officer

Parkinson Society British Columbia (PSBC) is thrilled to announce the appointment of Dr. Joanne Baker (PhD) as our new Chief Executive Officer (CEO), effective as she begins the transition process on Monday, May 6th. As we welcome Dr. Baker, PSBC extends heartfelt thanks to Jean Blake for her 10 years of dedicated service, with impacts reaching far and wide, and wishes her a fulfilling retirement. [\[learn more\]](#)

Seeking Support Group Facilitator

Parkinson Society British Columbia is currently seeking a volunteer support group facilitator for our in-person group in Langley. If you're interested in starting your own support group in your area, please don't hesitate to contact us. [\[learn more\]](#)

Join Our New Burnaby Support Group

Join our newly started virtual support group to connect with others who understand your journey. Share experiences, gain valuable insights, and find support in a welcoming environment. The group meets on the 4th Friday of each month from 1:00pm - 2:30pm. If you are interested in joining, contact our Education and Support Services Coordinator, [Alexandra Hernandez](#) for more information.

Join Our New Women Living with PD Support Group

We're thrilled to announce the launch of a brand-new support group tailored specifically for women living with Parkinson's! This virtual group aims to provide a safe and supportive space for women to connect, share experiences, and find solidarity in their journey with Parkinson's. Stay tuned for more details, including the date and time of the meetings. If you are interested in joining, contact our Education and Support Services Coordinator, [Alexandra Hernandez](#) for more information.

DISCUSSION TOPIC: Caregiving**Discussion Questions**

1. How can individuals with Parkinson's best communicate their needs and preferences to their caregivers, especially when facing cognitive or mood changes?
2. What strategies can individuals with Parkinson's employ to maintain a sense of independence and autonomy as their care needs evolve over time?
3. How can caregivers best recognize the signs of caregiver burnout, and what strategies can they employ to prevent or alleviate it?
4. How do you currently prioritize self-care in your caregiving routine, and what challenges do you face in maintaining your own well-being?

"Caregiver" is the traditional term used to describe an individual who is providing support and coordinating care for another person, and/or who may be responsible for most of the decision-making regarding the care of someone they know (Roland et al., 2018). The term "carepartner" is also used in place of, or interchangeably with the term caregiver. When an individual receives a diagnosis of Parkinson's disease (PD), a close family member, spouse, child, or friend often steps into the role of primary carepartner/caregiver. While specialized medical training isn't typically required, the key to effective caregiving lies in establishing a collaborative relationship with the person with Parkinson's.

When to Seek Professional Caregiving Help

As Parkinson's is a progressive condition, the role of a caregiver and the level of involvement evolve over time. In the early stages, the emphasis may be more on emotional support rather than hands-on care. It's crucial to personalize your understanding of "caregiving," especially when you might not feel like you are actively "giving" care, and the person with Parkinson's might not perceive themselves as needing care (Girard et al., n.d.).

Parkinson's disease progresses uniquely in everyone. Initially, you might only require occasional assistance with tasks like grocery shopping. However, as the disease advances, your needs may shift to include services such as a part-time home health aide. Eventually, full-time home

care or placement in a skilled nursing facility may become necessary. The caregiver has to determine how much they can and can't do themselves and what type of outside support is needed.

Here are some signs that indicate it may be time to consider hiring a professional caregiver:

- **Increased Care Needs:** If the individual with Parkinson's requires assistance with more advanced care tasks, such as mobility support, medication management, or specialized medical care.
- **Caregiver Burnout:** If the caregiver is experiencing physical, emotional, or mental exhaustion and is unable to meet the caregiving demands effectively.
- **Safety Concerns:** If the safety of the individual with Parkinson's is compromised due to the caregiver's inability to provide adequate care and supervision.

For individuals with Parkinson's who don't have a close friend, family member, or spouse as their primary caregiver or who live alone, recognizing when to hire or ask for professional caregiving help is equally important. There is no shame in seeking professional support. It is important to regularly evaluate your own abilities and time and be realistic about what you can do and what you will do (Getting Outside Help, n.d.).

By getting help, a caregiver can lessen their sense of isolation, and it gives you more confidence in your own caregiving ability. Having help increases your ability to think creatively and helps you get those needed breaks. Coming to terms with this reality of needing additional help and managing the emotions it evokes can be challenging. However, as the care needs of the individual with PD evolve, it's essential to continuously reassess the need for support for their caregivers as well (MacLean, 2023).

Managing the Caregiver-Person with Parkinson's Relationship

The relationship between the person with Parkinson's and the caregiver(s) is truly a care partnership. A PD diagnosis creates the need to negotiate new roles, responsibilities, and coping methods especially if it is a spouse, family member, or friend who steps into the role of a caregiver. The fatigue and motor difficulties of the disease can cause changes in a person's appearance and affect household roles. Cognitive and mood changes may make it hard to initiate and follow through on everyday tasks, which can be frustrating for both parties. As you adjust to these changes in your relationship, communication is important. Be aware of the ways that Parkinson's affects your loved one's ability to communicate (Parkinson's Disease, 2023).

Here are some tips to manage this relationship effectively:

- **Open Communication:** Be aware of the ways that Parkinson's affects your loved one's ability to communicate. Symptoms like slowness or a "masked" face that doesn't convey emotions can lead to frustration or misunderstanding for both parties. Carepartners may react to a Parkinson's diagnosis with denial, fear, or anger. Seeing your loved one change, particularly if mood or behavior are altered, can be hard to not take personally. Talking openly about what you are experiencing, clearly communicating on a day-to-day basis, and exercising patience are critical for both the person with PD and the carepartner. It is also crucial to ensure that your conversations are not always centred around the disease (Girard et al., n.d.).
- **Respect Autonomy:** Respect the individual's autonomy and involve them in decision-making processes as much as possible. Keep in mind that they have been independent and making decisions for themselves throughout their adult lives. Recognize that losing this self-sufficiency can be challenging for them, so it's essential to be understanding and respectful of their autonomy (Girard et al., n.d.).
- **Maintain Boundaries:** Set clear boundaries to balance caregiving responsibilities with personal space and independence. Learn to say no to demands that are unreasonable or unmanageable and determine your comfort level and limits when providing care. By

establishing clear and agreed-upon boundaries, the caregiving experience can often strengthen your relationship with the person you are caring for (Roland et al., 2018).

If you feel comfortable doing so, visiting a counselor or therapist together or individually can help you work through the many changes and emotions you are experiencing and learn how to have a healthy and supportive relationship.

Practical Tips for Caregivers

Establish a Routine

Creating a structured daily routine can help individuals with Parkinson's maintain a sense of normalcy and control. Consistency is key in managing symptoms and reducing anxiety for both the caregiver and the person with Parkinson's (Roland et al., 2018).

Educate Yourself

Knowledge is power when it comes to caregiving. Educate yourself about Parkinson's disease, its symptoms, progression, and management strategies. Stay informed about the latest research and treatment options to make informed decisions about your loved one's care. Whenever possible, accompany the person with Parkinson's to their medical appointments and ask questions of the doctor, nurse, and social worker (Holland, 2012).

Communicate Effectively

Open and honest communication is essential in any caregiving relationship. Encourage your loved one to express their feelings, concerns, and preferences. Listen attentively and validate their emotions, fostering a supportive and understanding environment (Roland et al., 2018).

Seek Support

You are not alone on this caregiving journey. Seek support from family, friends, support groups, and healthcare professionals. Joining a Parkinson's support group can provide valuable insights, practical tips, and emotional support from others who understand your experiences (Holland, 2012). Learn more about Parkinson Society BC's support groups at www.parkinson.bc.ca/supportgroups.

Take Care of Yourself

Probably one of the most important, and sometimes difficult, things caregivers can do is to take care of themselves. Self-care is crucial for caregivers to maintain their physical and emotional well-being. Make time for yourself, engage in activities that you enjoy, and prioritize your own health and happiness. Whenever possible get your sleep, take breaks, make and keep social activities, and try to keep your sense of humor. Remember, you cannot pour from an empty cup, so taking care of yourself is essential to effectively care for your loved one with Parkinson's (Roland et al., 2018).

Make Time for Fun

As much as possible, continue to engage in the activities you've always enjoyed. Whether it's attending a book club, participating in a swim class, or having lunch with a friend, maintaining your identity separate from your role as a caregiver is crucial for your mental and physical well-being (Girard et al., n.d.).

Caregiving is a multifaceted journey that affects not only the individual diagnosed but also the caregiver, who faces unique challenges throughout the progression of the disease. Caregiving can be both rewarding and challenging. It is essential to establish a strong and supportive relationship between the caregiver and the person with Parkinson's. To navigate the challenges that come with the progression of the disease, open communication, respect for autonomy, and maintaining clear boundaries is crucial. It is also important to educate oneself about Parkinson's, establish routines, and seek support from various resources to be an effective caregiver. Most importantly, caregivers must prioritize self-care to maintain their physical and emotional well-being. Remember, a well-supported caregiver is better equipped to provide the necessary care and support to their loved one with Parkinson's.

Additional Resources

- A Comprehensive Guide for Parkinson's Caregivers [[booklet](#)]
- Asking for and Accepting Your Own Support [[read more](#)]
- Caring for Someone with Parkinson's [[brochure](#)]
- Caring in the Family [[helpsheet](#)]

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