

VIEWPOINTS



WINTER 2020

A QUARTERLY NEWSLETTER
BY PARKINSON SOCIETY
BRITISH COLUMBIA

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OUR MISSION

Parkinson Society British Columbia exists to empower people with Parkinson's in British Columbia through providing resources and services to enable self-management, self-reliance, and self-advocacy.

YOUR SUPPORT IS ESSENTIAL

Parkinson Society BC would not exist without the support of our members, donors, and volunteers. Here are a few of the ways you can support your Society:

Membership: For an annual fee of \$25, your household benefits from unlimited access to our education and support services, events, and resources.

Donations: Contact us to set up monthly, quarterly or annual donations, or think of us when giving through United Way.

Special Events: Ticket sales from our educational and fundraising events support the Society's programs and services.

Planned Giving & Bequests: Consider Parkinson Society BC as a beneficiary in your will.

Fundraising: Become a Champion for Parkinson's by organizing your own event benefiting the Society.

For more information on how you can support us, visit www.parkinson.bc.ca/donate.

SUPPORT GROUPS

Our network of over 50 volunteer-led support groups provide people with Parkinson's, and their caregivers and families, an opportunity to meet in a friendly, supportive setting. For our full support group listings, visit www.parkinson.bc.ca/groups.

100 Mile House, Abbotsford, Burnaby, Campbell River, Carepartner Online, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, Duncan/Cowichan Valley, Kamloops, Kelowna, Kelowna Carepartners, Kelowna West, Kootenay Lake East Shore, Langley, Langley YOPD, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Nanaimo, Nanaimo Carepartners, New Diagnosis (Vancouver), New Westminster, North Shore, Osoyoos/Oliver, Parksville/Qualicum, Parksville/Qualicum Caregivers, Port Alberni, Powell River, Prince George, Quesnel, Richmond, Richmond Carepartners, Sunshine Coast (Sechelt), Surrey, Trail/Castlegar, Tri Cities, Tri Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Carepartners, Vancouver Downtown Working Professionals, Vancouver West Side, Vernon, Vernon Caregivers, West Vancouver Carepartners, White Rock, White Rock Carepartners, Williams Lake, Young Onset Parkinson's Online

EDITORIAL STATEMENT

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HOLIDAY MESSAGE



This year, you placed your faith in us to support you through the unprecedented COVID-19 pandemic. At Parkinson Society British Columbia, we understand how uniquely challenging this time has been for our community. To help ensure the safety of our members across the province and encourage physical distancing, we moved our programs and services online, giving you access to the resources you need, all from the comfort and safety of your own home. Our dedicated staff worked hard to bring you new online events every week, including webinar presentations with expert speakers; workshops like improv, drumming, dance,

and SongShine; and Parkinson's-specific exercise classes for all levels of mobility. In October, we also brought our provincial conference, *Moving Forward, Together*, to the virtual stage, with presentations from leading Parkinson's researchers, physiotherapist-led movement sessions, and an online exhibition hall.

Throughout the past year, we have been committed to staying accessible to you, no matter the circumstances. Our clinical counsellors continued lending their compassionate care online and over the phone, while our support services staff offered their expertise via email and through our information and referral hotline. To reach those with limited access to the internet, we mailed out hundreds of copies of select educational resources. And to keep you socially connected, we helped support groups transition to phone and video meetings, and stayed in touch with individual members through friendly and supportive phone calls.

The Society focused its advocacy efforts this year on providing incentive funding to support the hiring of allied healthcare professionals (AHCPs) in both the Interior and Island Health Authorities. AHCPs provide a comprehensive, multidisciplinary approach to the care of people affected by Parkinson's. Allowing people to live independently for longer not only improves quality of life, but reduces the overall impact on the healthcare system by decreasing hospital admissions due to issues such as aspiration or fractures. In the Okanagan, we provided funding in the amount of \$445,000 to support a part-time physiotherapist, a part-time speech-language pathologist, and a part-time social worker, over five years. On the Island, we provided \$498,000 to fund a full-time speech-language pathologist over five years.

As the year comes to a close, our hearts are with those who have suffered hardship in this pandemic. We hold on to hope for brighter days ahead in the year to come. Despite these challenging times, we are here to support and empower you.

Once again, we are grateful for your trust and confidence in the Society. We look forward to serving you in 2021.

Warm wishes for a joyful holiday season, and a happy new year.

With gratitude,

A handwritten signature in cursive script that reads "Jean Blake".

Jean Blake, Chief Executive Officer
Parkinson Society British Columbia



ASK AN EXPERT

Elaine Book and Gila Bronner discuss sexual health and intimacy in Parkinson's



Elaine Book, MSW, RSW has worked in the field of social work for over 30 years in a variety of community and hospital settings, with an interest in the geriatric population. She is the Center Coordinator and Clinic Social Worker for the Pacific Parkinson's Research Centre at the University of British Columbia (UBC) in Vancouver, Canada. She is also

a Clinical Instructor in the Faculty of Medicine in the division of Neurology at UBC. She has become a leading speaker and presenter in the Parkinson's community, and serves as a mentor with the Parkinson Foundation, a planning committee member of the World Parkinson Congress, and a member of the Parkinson Canada Medical Advisory Council. Elaine has also been active in research projects focusing on coping with Parkinson's and the role of social work in providing care to people with Parkinson's disease and their carepartners.



Gila Bronner, MPH, MSW, CST is one of the leading sex therapists in Israel, and a world-renowned expert in sexual rehabilitation in neurological disorders. Gila is the Founder and Director of Sex Therapy Services at the Sheba Medical Center in Ramat-Gan, Israel. She trains healthcare professionals in sex education,

and helping their patients to cope with issues of sexual rehabilitation. She also specializes in treating patients with Parkinson's, Huntington's, epilepsy, multiple sclerosis, and stroke. Gila's international work includes lectures and workshops in Europe, North America, Asia, and Australia. She has also spoken at the Movement Disorder Society Congress and the World Parkinson Congress.

How common are concerns around sex and intimacy among people with Parkinson's disease?

EB: Concerns around sex and intimacy are very common, as there are a number of factors related to Parkinson's disease (PD) that can result in challenges in sex and intimate relationships. Some of these factors, which can affect both people with PD and their carepartners, include physical factors like pain, fatigue, and motor symptoms, or emotional factors like depression, anxiety, apathy, or shame. There are also common sexual function diagnoses, such as erectile dysfunction (ED), low sexual desire, or hypersexuality, that can often contribute to sex and intimacy concerns.

What are some effects Parkinson's may have on an individual's sex life? How are men and women impacted differently?

GB: Our sexual functioning is affected by our mood – people with Parkinson's and their carepartners may experience a higher frequency of depression and anxiety due to the challenges of the disease, which may in turn affect the ability to experience desire and sexual excitement. Parkinson's can also cause a lack of motivation, which may inhibit someone from initiating intimate activities. The motor symptoms of Parkinson's can also have a significant impact on an individual's sex life. For example, bradykinesia or tremors negatively affect fine motor ability, which allows for the gentle, rhythmic touch and movement involved in sexual activity. These difficulties in movement create distractions, which can cause men to lose an erection or cause women to lose lubrication, reducing the ability to orgasm. Motor symptoms can also affect the ability to give and receive pleasant, non-erotic intimate touch, such as hugging or holding hands.

How can certain common medications that people with Parkinson's take contribute to changes in sexual function?

GB: Antidepressants are one class of medications that may contribute to decreased desire and sexual ability. Some individuals with PD report a feeling of heaviness while

on these medications, affecting their ability to get aroused or reach orgasm. On the other hand, the dopaminergic treatments often used to treat motor symptoms of Parkinson's can cause increased sexual desire and hypersexuality. When this occurs, the person with PD experiences these heightened feelings as a result of their medications, while their partner continues to experience normal or even lower levels of desire – this gap is referred to as sexual desire discrepancy. Talking to your doctor about an adjustment in medication or seeking advice from a therapist can help you work towards closing this gap and improving sexual function.

What are some common treatment options or strategies that may help individuals improve their sexual health, and what are some overall benefits of a healthy sex life?

GB: Increasing understanding and awareness is one key strategy. Educating people with Parkinson's on the effects that different medications may have, or the challenges they may face in regards to sexuality, may provide insight into their options and a sense of relief. It is beneficial to understand sexuality as a holistic, comprehensive matter. Sex is not simply a physical act. Intimacy includes non-erotic activities like hugging, touching, talking, and feeling close to one another. Increasing these non-erotic acts often positively impacts general health concerns like pain, stress, and anxiety, and may help to restore an intimate connection between couples experiencing sexual dysfunction. Additionally, planning sexual activity for times when you feel better may reduce distractions and anxiety, while using things like ED medications, oils, or lubricants may be recommended to treat specific concerns.

Sexual health questions may be uncomfortable for some people to address with their doctors. Do you have any advice on how a discussion on this topic can be approached, and why it is important?

EB: Sexual health questions are important because sex and intimacy impacts quality of life significantly, and thus it is worthwhile to address any changes in this area, whether it is related to PD or other health conditions. Remember, sex and intimacy are normal parts of life, and it is normal to have challenges in this domain whether you have a health condition or not. This may feel like a taboo or embarrassing topic, but

SAVE THE DATE

On February 11, 2021, Elaine Book will be joined by Parkinson Society BC's own clinical counsellor, Tricia Wallace, for a webinar on intimacy in Parkinson's. This presentation will cover challenges with sexual intimacy, and explore options to address emotional distance influenced by physical limitations and role transitions brought on by Parkinson's disease

Details and registration coming soon. Stay tuned to our website at www.parkinson.bc.ca/events.

it is not! Your physician and healthcare providers are there to help address health issues in your life, including sexual health concerns. If you are not asked by your healthcare providers about your sexual wellness, advocate for yourself, share your concerns, and be honest. Talk about your concerns with your partner before your visit, and consider attending appointments together so that you are on the same page.

What specific steps can a person with Parkinson's take if they are experiencing concerns about their sexual health?

GB: Firstly, find a healthcare professional that you trust and feel comfortable sharing intimate details with, whether that is your neurologist, family physician, or a nurse. They are there to help you, and you can ask them to refer you to someone who may be more specialized to treat sexual health concerns. Men may be referred to a urologist, as they can help with issues like ED and premature ejaculation, and women may be referred to a gynecologist for issues such as painful sex or vaginal dryness. Finding a sex therapist or a relationship counsellor, and working with this kind of expert as a couple, may help to address any relationship issues that have arisen due to sex and intimacy concerns. The most important thing to remember is that there is help available.

How can spouses or partners in caregiving roles maintain healthy intimacy with their loved ones with Parkinson's?

EB: One key to balancing intimacy with meeting care needs is to practice self-care. In order to give and receive in a relationship, you as the carepartner need

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LIVING WELL

Impulse control disorders in Parkinson's

Impulse control disorders (ICDs) are common in people with Parkinson's disease (PD) who also take dopamine agonists, a class of drugs often used to treat the symptoms of PD. Behaviours like compulsive gambling, hypersexuality, excessive spending, or binge eating are some of the most common behaviours seen in ICDs. Individuals with an ICD often feel urged to engage in harmful behaviours repeatedly, and lack self-control over these behaviours, leading to emotional distress. ICDs can have a significant impact on quality of life for the individual and their loved ones – however, management techniques and medication adjustments can often control or even eliminate these disorders.

Recognizing impulsive behaviours

According to Grant et al. (2013), ICDs are characterized by the following:

- engaging in ongoing, obsessive, or destructive behaviours despite negative consequences
- a progressive lack of control over these behaviours
- an intense urge or craving to engage in these behaviours
- a sense of relief or pleasure once these behaviours are performed

Impulsive behaviours can take many forms, and at times, can be difficult to identify. Many people with ICDs can even be aware of their bad behaviours, and fully understand their consequences. The problem lies in an inability to resist or control their impulses. Some individuals may feel a sense of embarrassment or shame for engaging in certain behaviours, and make excuses to justify them.

This is an important distinction that reveals whether one's tendencies are a

result of a cognitive disorder or a behavioural one. In contrast to ICDs and similar issues, cognitive disorders are largely categorized by a person's inability to understand right and wrong. If you notice that a loved one is displaying behaviours that they are unable to recognize as wrong or harmful, or you are having trouble identifying issues you may be experiencing yourself, seek help from a healthcare professional.

Dopamine agonists & ICDs

Dopamine is a neurotransmitter, a chemical released by brain cells (neurons), in order to communicate with other nerve cells. It plays a role in motor function, hormone release, and decision-making. Parkinson's causes the cells that produce dopamine to die off, resulting in a low supply of the neurotransmitter. Without enough dopamine, motor symptoms of PD arise.

Dopamine cannot be given directly as a treatment, because it cannot pass from the bloodstream to the central nervous system. Instead, medications like levodopa or dopamine agonists (DAs) are used to address dopamine depletion.

Levodopa is a building-block of dopamine, and is used to naturally stimulate production of the neurotransmitter in the brain. It is the most effective drug treatment for PD, but it can often cause severe motor fluctuations, called dyskinesia, after prolonged use. DAs are frequently prescribed in combination with, or instead of levodopa. Unlike





Always consult your doctor before adjusting or stopping any medication.

levodopa, which has to be converted into dopamine in the body, DAs have a more immediate release, and tend to last longer in the body. Popular DAs include Mirapex (pramipexole), Requip (ropinirole), and Neupro (rotigotine).

Although DAs have fewer movement-related side effects compared to levodopa, individuals may experience other side effects such as nausea, hallucinations, sudden sleepiness, and dizziness or light-headedness. DAs also significantly increase the risk of developing ICDs.

In a longitudinal study of over 400 people with PD, the risk of developing an ICD for those who had taken a DA was found to be 52%, compared to a risk of only 12% for those who had not been exposed to a DA (Corvol, 2018). Although the prevalence of ICDs is unknown, studies suggest that the risk for developing ICDs is highest among younger males, those with a personal or family history with addiction, and those with symptoms of depression, irritability, and changes in appetite (Pontone, 2018).

Evaluating and managing ICDs

If left unaddressed, ICDs can have very serious consequences, including health risks, financial ruin, divorce, or loss of employment. An ICD can often make the person experiencing it feel helpless, shameful, or embarrassed, causing them to lie and hide their behaviour. Though difficult, it is extremely important to recognize

that these behaviours are not the individual's fault — an ICD should be regarded as a medical condition that can be effectively treated. In order to identify and prevent the progression of ICDs, it is important to be knowledgeable about the risks and potential causes, and to remain open and honest about your experience with healthcare professionals and loved ones.

Treatment often involves discontinuing the use, or lowering the dose, of any DA believed to be linked to ICD symptoms. Some individuals may be

switched to levodopa if not already taking it, or the dosage of levodopa may be increased to counteract the effects of the DA. Adjusting medications can present challenges, as stopping or reducing DAs can sometimes cause withdrawal symptoms or other unwanted side effects, such as decreased motor control. Thus, it is important to continue working with your neurologist and healthcare team to find the most effective combination of medications.

Solutions for ICDs may also focus on behavioural changes. These strategies may include, for example, removing access to credit cards and internet browsing to restrict shopping, gambling, and the viewing of pornography. Seeking support from a counsellor can help to identify and change disruptive behaviours associated with ICDs and navigate emotions to cope in a more adaptive way. Additionally, individuals can work with loved ones to distract themselves and fill the time they spent engaging in these negative behaviours with more positive activities, such as socializing with friends, learning a new skill, or spending time outdoors. While symptoms of ICDs can be upsetting, these treatment options often result in significant improvement.

How carepartners can help

It may be troubling as a carepartner to see your loved one with PD struggling with an ICD, and you may feel helpless to stop it. However, there are some things you can do to intervene. Here are some ways you can help ensure your loved one receives the treatment

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ASK AN EXPERT: SEXUAL HEALTH & INTIMACY CONT'D

to be physically, mentally, intellectually, and socially well taken care of. Also, consider changing up or delegating some of the challenging or more time-consuming tasks associated with caregiving to make time and space for an intimate connection with your loved one with Parkinson's.

Is there anything else you would like to add?

EB & GB: Whether you are single or with a partner, think about and/or communicate your intent to have more intimacy in your life, then come up with a realistic plan as to what that looks like and how it will happen. If intimacy has been missing for some time, start slow and have reasonable expectations. A small change like a daily kiss or expression of gratitude can make a big difference. Make it a priority and be proactive – there are a lot of resources available with suggestions of steps you can take to maintain or improve your intimate life. Don't give up, every person has a right to have a satisfying and positive sex life.

Additional Resources

Sex & Intimacy | Helpsheet | bit.ly/pdintimacy

YOPD Sexual Health | Video | bit.ly/yopdintimacy

Maintaining Sexual Health While Coping with Parkinson's | Video | bit.ly/maintainingintimacy

Sex Therapy | Counselling BC | bit.ly/sextherapybc

Counselling

Parkinson Society BC offers free, short-term counselling for anyone affected by Parkinson's disease. Our clinical counsellors can offer support to people with Parkinson's and their partners dealing with many issues related to intimacy, relationships, and sexual wellness.

To learn more about our counsellors and how they can help you, visit www.parkinson.bc.ca/counselling or contact us at counselling@parkinson.bc.ca.

LIVING WELL: IMPULSE CONTROL DISORDERS CONT'D

they need (Davis Phinney Foundation, 2020):

- Educate yourself by obtaining all the details on ICDs before your loved one with Parkinson's begins dopamine agonist therapy – prevention is one of the best treatments.
- Do not be afraid to ask your loved one about unusual behaviours like random absences, unexplained changes in finances, and other forms of secrecy.
- Inform the person with PD's doctor if you notice any potential signs of an ICD.
- Treat ICD symptoms as medical concerns, not personal weaknesses – avoiding blame will make your loved one will feel more comfortable opening up.
- Work together with your loved one with PD, and a healthcare professional, to develop a plan on how to address and manage ICD symptoms.

By taking these steps as a carepartner, you can ensure your loved one receives proper medical attention and does not feel alone while facing the challenges of an ICD.

Additional Resources

Talking to Your Doctors | Helpsheet | bit.ly/paceframework

Mood Changes | Helpsheet | bit.ly/pdmoodchanges

Parkinson's Medication | Helpsheet | bit.ly/pdmedication

Medication Video Series | bit.ly/pdmedseries

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VOLUNTEER RECOGNITION

Above & Beyond Awards 2020

Parkinson Society British Columbia (PSBC) recognizes people with Parkinson's and their caregivers who have gone above and beyond with others in their communities, and who demonstrate a passion to celebrate each day with joy, compassion, and understanding.

These individuals are true examples that people affected by Parkinson's disease (PD) can live rich, full lives. They make an effort to open up new opportunities and foster relationships they had never imagined possible before their diagnosis.

We have been very fortunate to meet and work together with these individuals, but we know that there are many more inspiring stories. PSBC would like to highlight these dedicated individuals.

Volunteer of the Year

Ron Corbett

As the Prince George support group facilitator, Ron helped nurture a positive, inclusive, and hopeful atmosphere, where people affected by Parkinson's could come to share their thoughts, feelings, and experiences without judgement. The Prince George support group is consistently one of the strongest and most well-attended in the province, which is a true testament to Ron's leadership. Ron's involvement with Parkinson SuperWalk and Parkinson's Awareness Month has helped bring attention to the programs and services offered by the Society, as well as extend knowledge of the lived experience with Parkinson's to the public. Ron retired this year after seven years in the facilitator role.



Special Recognition

Terry Meade

Terry is an active member of the Parkinson's community in Kamloops and contributes his time and energy to supporting people with Parkinson's

disease. He encourages and inspires the PD community to remain active and engaged through various events such as SuperWalk and the Step-by-Step walking program. Terry is a very positive and welcoming advocate in the Parkinson's community and continues to go out of his way to help others navigate the challenges associated with PD.

Debbie Hartley

Debbie is an inspiring and engaging volunteer who sets a great example for others living with Parkinson's disease. She provides consistent and ongoing support to participants in the Kelowna support group, and makes newcomers feel warmly welcomed with her cheery, optimistic, and positive personality. Debbie is an advocate for PD, and is involved in many local events and fundraisers helping to spread awareness for the PD community.

Rendy Olthuis

Rendy has been the facilitator of the Kamloops support group for many years, and continues to be a great source of support for people with Parkinson's. Her hard work and dedication to the Parkinson's community is appreciated by everyone she meets. Rendy is a compassionate and caring leader that others have described as 'an inspiring role model'.

Susan Aronson

Susan has been the facilitator of the Nanaimo support group for several years and has made this growing group the success it is today. She is always eager to help members find the most valuable resources to guide them through their journey with Parkinson's. Susan is a true leader whose charisma and enthusiasm encourages others.

Other Nominees

We gratefully acknowledge the significant contributions of each of our Above and Beyond Award nominees this year, including:

- Alf Todd
- Betty Clarke
- Chris Olsen
- Colleen Vollan
- Darell Miton
- Edith Elliott
- Margaret Elson
- Pat Mauch
- Wendy Olinger

PARKINSON SUPERWALK®

This year, Parkinson SuperWalk celebrated its 30th anniversary. Despite the challenging circumstances, your incredible support has helped raise \$300,610 and counting. These funds directly support Parkinson Society BC's mission to empower people with Parkinson's by providing resources and services to enable self-management, self-reliance, and self-advocacy. Thank you to everyone who participated, donated, and volunteered this year. Your resiliency, particularly in these uncertain times, demonstrates your unwavering commitment to the cause.

Total: **\$300,610**
...AND COUNTING!





TOP TEAMS

BC Teams (Raised \$1,000+)

A&W Cruisers, Are we there yet?, Century House Parkinson's Group, Dopamine Queens, Hope, In Memory of Doug Seaward, Manuel Walkers, Nanaimo PD Support Group, Oceanside PD Warriors, ParKrahn, PERCS for Parks, **Red Hot Chili Steppers (Top Team in BC)**, Remembering The Dude, Rock'n'Mama and the Followers, Saskatchewan Roots, Shake Señora, Shake, Rattle & Roll, Shrimp, Stan the Man, Stir It Up, Team Barry, Team Elizabeth, Team Gran, Team Hennebery, Team Janet, Team Jeanette!, Team M&C Boschman, Team Mojo, Team Val, When Life Gives You Parkinson's, This isn't the beer and chocolate tasting, Walk4Pake, Wray's team

Thank you to our
Provincial Sponsors



980 CKNW

For the most up-to-date
walk totals and photos, visit
parkinson.bc.ca/sw-totals.

TOP INDIVIDUALS

Superb SuperStar Walkers (Raised \$5,000+)

Deborah Hartley, Elizabeth Holroyd, Charlotte Kennedy, Wendy Olinger, **Shelley Schreyer (Top Fundraising Individual in BC)**, Janet Stuehmer, Valerie Swannell, Carole Taylor, Garry Toop, Colleen Vollan, Deborah Yeates

SuperStar Supreme Walkers (Raised \$2,500 - \$4,999)

Elspeth Banerd, Wayne Benning, Merv Boschman, Tracey-Lee Eddy, Margaret Elson, Jeanette Fisher Pynn, Terence Gorsuch, Angela Hutchinson, Madeline Kennedy, Carolyn Krahn, John Manuel, Eva Moser, Wendy Murray, Margaret Mutch, Holly Parrish, Chris Parrish, Sally Pollock, Allen Sundvall, Valerie Zilinski

SuperStar Walkers (Raised \$1,000 - \$2,499)

Sylvia Bull, Linda Dawson, Emer Dubois, Nigel Fitzpatrick, Janice Gibbon, Karen Giesbrecht, Jill Goertzen, John Hallam, Penny Henderson, Margaux Hennebery, Janice Hobbs, Jerry Joseph, Jasdeep Khurall, Philip Konrad, Deborah Lang, Terry Leitner, Kathy Lynn, Leanne Mah, Richard Maki, Wray McDonnell, Kevin McDowell, Harry Oda, Anna Oenema, Rendy Olthuis, Doug Pickard, Tiffany Prystay, Patricia Rupper, Karla Seaward, James Stevenson, Geoffrey Swannell, Courtney Vasquez

All results have been alphabetically sorted by category, then name. For a list of monetary totals, please visit www.parkinson.bc.ca/sw-totals.

We endeavour to provide accurate listings using the information available at the time of publishing. If there is information you are aware of that has been overlooked, please contact us.

THANK YOU, BRITISH COLUMBIA!

LIVING WELL

Tax tips and financial resources for people with Parkinson's and carepartners

With tax season fast approaching, it is important for people with Parkinson's and their families to be equipped with an understanding of all the financial resources that may be available to them. Financial hardship disproportionately affects people with disabilities, due to factors such as unemployment, and increased medical and home modification expenses (PHAC, 2014). For many Canadians, the COVID-19 pandemic has added further stress on their financial health.

Though many Canadians believe the economy is still weakening, experts say that conditions are slowly improving (CBOC, 2020). While Canada is recovering, Parkinson Society BC is here to remind you that you are not alone. We are here to provide you with practical, accessible information and resources to help you manage your finances during these uncertain times.

Note: information provided in this article is intended to be used for general information only, and should not replace consultation with a personal finance or tax professional.

Tax Benefits for People with Disabilities

Disability Tax Credit

The non-refundable disability tax credit (DTC) helps people with disabilities or their carepartners reduce the amount of income tax they have to pay. The purpose of the DTC is to encourage equity by accounting for the unavoidable expenses that people with disabilities face. In 2019, the maximum disability amount was \$8,416.

You may qualify for the DTC if you experience severe and prolonged physical or mental impairments which affect you at least 90% of the time. These impairments must also have lasted for a continuous period of 12 months or longer. It is important to note that eligibility for the DTC is not simply based on a disease diagnosis. Rather, symptoms and impairments on a person's ability to effectively complete basic daily activities – such as walking, communication, or feeding and dressing oneself – will be considered.

To apply for the DTC, individuals must complete Part A of Form T2201, the Disability Tax Credit Certificate, and have a medical practitioner fill out Part B. The form must then be submitted either electronically through CRA *My Account*, or mailed to your tax centre. The CRA will assess your application and send you a notice of determination with their decision, including instructions on how to claim the disability amount on your tax return, if applicable. If you qualify for the DTC and could have claimed it in the past but did not, you may also re-submit prior tax returns for adjustment.

Medical Expense Tax Credit & Disability Supports Deduction

The medical expense tax credit (METC) is available for medical expenses prescribed by a doctor and paid for in the current tax year. Your claim may need to be supported by certain documents, including original receipts, prescriptions, certification in writing, or a Form T2201. Do not send these documents with your tax return, but be sure to keep them on hand in case the CRA asks to see them later.

You can only claim the part of an eligible expense for which you have not been, or will not be, reimbursed. If you pay a deductible on private insurance, that amount can be claimed, plus the monthly premiums you pay for the insurance (with the exception of MSP), together with the non-reimbursed portions of the expenses. Common eligible medical expenses may be viewed at bit.ly/commonmedicalexpenses.

Home Accessibility Tax Credit

The non-refundable home accessibility tax credit (HATC) allows qualifying individuals to claim up to \$10,000 per year in eligible expenses. Qualifying renovations must allow you to gain greater access or increased mobility within your home, or a relative's home if you live there. For instance, this could include a wheelchair ramp, walk-in bathtubs or showers, or grip bars. Eligible expenses must be supported by documentation such as agreements, invoices, and receipts. Renovations can be made for someone who is at least 65 years of age, or otherwise eligible for the DTC.

Canada Caregiver Credit

The Canada caregiver credit (CCC) is a non-refundable tax credit that may be available to an individual who supports a spouse, common-law partner, or a dependant with a physical or mental impairment.

The amount you can claim depends on your relationship to the person for whom you are claiming the CCC, your circumstances, the person's net income, and whether other credits are being claimed for that person. For your spouse or common-law partner, or an eligible dependant above 18 years of age, you may be entitled to claim an amount of \$2,230 in the calculation of lines 30300 or 30400, respectively. You could also claim an amount up to a maximum of \$7,140 on line 30424.

Canada Workers Benefit

In 2019, the refundable Canada workers benefit (CWB) replaced the working income tax benefit (WITB). The CWB provides tax relief for eligible low-income individuals and families, as well as a disability supplement for individuals who have an approved Form T2201 on file.

To apply for the credit and supplement, you must complete Schedule 6 in your tax package or certified tax software. Enter the amount from line 42 of Schedule 6 on line 45300 of your income tax return, and file your return with the CRA (if you prepared your return on paper, include your completed Schedule 6 with your return). The maximum payment for the CWB is \$1,355 for single individuals and \$2,335 for families. The maximum payment for the disability supplement is \$700 for both single individuals and families.

Budgeting & Saving Resources

Registered Disability Savings Plan

The registered disability savings plan (RDSP) is intended to help DTC-eligible individuals save for long-term financial security. Similar to RRSP plans, an RDSP is a tax-deferred savings plan. Contributions can be made until the end of the year in which the beneficiary turns 59 years of age. For every \$1 put in an RDSP account, the federal government can (if your family income is below \$97,069) match it with up to \$3 (the Canada Disability Savings Grant). Additionally, for people living on a low-income (less than \$31,711), the federal government will put in \$1000 each year for 20 years (Canada Disability Savings Bond). Visit www.rdsp.com to learn more about how this plan may benefit you or someone you love.

Canada Pension Plan Disability Benefits

The Canada Pension Plan (CPP) provides disability benefits in some circumstances. If the symptoms of Parkinson's disease are contributing to your decision to retire early, you should consider applying for CPP

disability benefits instead of an early CPP retirement pension. To qualify for the CPP disability benefit, you must be under age 65, meet the minimum qualifying period, and have a severe and prolonged disability. Additionally, in order to be eligible for CPP disability benefits, you have to prove that your medical condition prevents you from doing any paid work.

CPP disability benefits typically provide more income than an early CPP retirement pension. The monthly amount of the disability benefit is based on the contributions made to the CPP prior to your application.

Personal & Professional Budgeting Tools

During these uncertain times, identifying a concrete budget that categorizes 'needs' versus 'wants' is a useful way to manage your finances – after evaluating your spending, consider redirecting any extra money into an emergency fund equivalent to 3-4 months' worth of expenses (FCAC, 2020).

The Financial Consumer Agency of Canada (FCAC) offers an online Budget Planner to help you get started on creating and managing your budget on an easy-to-use platform. They also offer many other resources on budgeting, savings, debt management, and interactive tools to help you maintain good financial health during these challenging times.

Another practical option to ease financial concerns is to reach out to financial professionals and institutions. A financial advisor may be able to help you protect and grow your savings while managing the costs associated with Parkinson's.

COVID-19 has caused many financial institutions to offer forms of financial relief to their clients, such as deferring mortgage or credit card payments, lowering credit card and loan interest rates, or taking out a home equity line of credit. While these choices could be beneficial, it is important to fully understand the conditions and long-term implications of each. Contact your financial institution to explore your options further.

Finally, take advantage of valuable free online resources for people with Parkinson's. PSBC has many educational and exercise webinars, free legal services (for PD related concerns), counselling, and a large collection of accessible resources on various topics, including finances. Visit our website to view all our upcoming events and resources, as well as other organization's events and programs, at www.parkinson.bc.ca/events.

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GIVING

Shelley Schreyer's road to raising \$50,000

Shelley Schreyer was diagnosed with Parkinson's disease (PD) in 2015. Although they had suspected PD based on her symptoms, Shelley and her loved ones were shocked. With no history of the disease in their family, it was hard to wrap their minds around the diagnosis, and it was an emotional time for everyone.

Over the coming weeks and months, Shelley and her family began adjusting to life with Parkinson's.

"I wish I could name everyone that has supported me over the last five years, but there are too many."

As soon as she learned of her diagnosis, Shelley's husband, Cory, educated himself on the different stages of PD. He continues to attend all of Shelley's neurology appointments as her biggest supporter. Cory is often able to provide the doctor with extra information about Shelley's symptoms from a carepartner's perspective, which helps Shelley get the best possible treatment.

Shelley has also received immense support from different organizations. Right after her diagnosis, she found Parkinson Society British Columbia (PSBC) and

started attending the Society's many seminars and events for people with Parkinson's, encouraging her and strengthening her understanding of the disease. Shelley's employer adapted to her needs and enabled her to continue working for as long as possible after her diagnosis. Although she can no longer work today, her previous employer continues to offer support to the Parkinson's community by sponsoring the local Kelowna Parkinson SuperWalk, and donating to Shelley's fundraising events.

While Shelley's diagnosis has brought challenges for her and her family, it has also inspired growth, and moments of happiness. Parkinson's has changed the way she sees challenges and obstacles in life, now viewing them as minor bumps in the road. "Each day is different with this disease, so you learn to roll with the punches," she says, "I celebrate the wins and move on from the losses." She recalls back to day one of her diagnosis and how happy she was to have Cory, her pillar of strength, sitting beside her – over the years, they have faced the disease side by side. Shelley has also gained new friendships with people from the community who understand each other's experiences and laugh together.

After seeing first-hand the need for education and research in the Parkinson's community, Shelley was





“Each day is different with this disease, so you learn to roll with the punches. I celebrate the wins and move on from the losses.”

inspired to embark on a journey to raise \$50,000 in lifetime giving, and she recently achieved this incredible goal. While the COVID-19 pandemic created some challenges in fundraising this year, she remained determined and focused. She drew on the excitement of reaching her goal to keep her motivated, and used social media to reach as many people as she could while physically distancing.

During her years-long fundraising journey, Shelley was surprised by the generosity and support she has received, not only in monetary donations, but also in the volunteer efforts of her supporters, who have shown up to lend a hand at fundraising events like SuperWalk, year after year. For anyone wishing to start fundraising themselves, Shelley encourages them to start small by asking friends and family to donate. Even something as simple as collecting recycling from neighbours year-round can help raise

money. Another option is to plan fun community fundraising events, with activities like wine wall raffles, gift card raffles, or bingo.

Shelley’s message to people with Parkinson’s is to stay positive, active, and joyful – celebrate the wins! Educate yourself as much as possible and connect with the Parkinson’s community by getting involved in webinars and activities, joining a support group or exercise group, and showing your support for fundraising initiatives that improve the lives of people with Parkinson’s.

Parkinson Society British Columbia is thankful for generosity of individuals like Shelley Schreyer. Without the support of our volunteers, donors, and members across the province, none of our work would be possible. To learn more about how you can support PSBC, please visit www.parkinson.bc.ca/how-to-help.

NEWSWORTHY

UPCOMING EDUCATION EVENTS

Holiday Social & Caroling

It's a Merry Acoustic Holiday! Connect with others and spread some holiday cheer in this virtual holiday social event. On December 10, Joani Bye and Mary Pettinger lead us in a holiday caroling sing-along. Don't forget to wear your favourite festive sweaters!

Date: Thursday, December 10
Time: 1:00pm - 2:00pm
Capacity: 50
Cost: Free

SongShine with Joani Series

This program harnesses the power of the brain, breath, and emotion to reclaim voices. Joani Bye and Mary Pettinger will engage participants in six uplifting sessions of SongShine, a program using singing, breath work, diction, articulation, and creative imagination exercises to strengthen voices affected by Parkinson's or other neurological challenges. SongShine's goal is to help you communicate more easily and clearly, while facilitating a sense of community, camaraderie, and confidence in the process!

Join Joani and Mary for immersive, holistic, and fun sessions that will include the following:

- Singing favorite songs
- Relaxation
- Breathing exercises
- Tongue exercises (for articulation and swallowing)
- Linguistic and vocal instruction
- Imagination exercises

Dates: Thursdays, January 7, 14, 21, 28,
February 4, & 11
Time: 1:00pm - 2:00pm
Capacity: 50
Cost: Free

New Diagnosis Workshop Series

Have you been diagnosed with Parkinson's disease in the last two years? Join us for our New Diagnosis Workshop Series in February 2021.

Movement disorder neurologists, Drs. Jonathan Squires and Melissa Mackenzie, and physiotherapist Michelle McCarthy from the Movement Disorders Clinic at the UBC Centre for Brain Health, will lend their knowledge to provide an overview of the disease, treatment options, and tips on staying active to help slow the progression of symptoms.

This workshop will also feature a panel of all three speakers for a final 30-minute question and answer session at the end of the series, giving attendees an opportunity to ask questions about their Parkinson's diagnosis, management, treatment, and support.

Only one registration is required to attend all sessions in this series. This series is free for participants. Please see full session details below.

Parkinson's and Diagnosis

Dr. Jonathan Squires, Movement Disorder Specialist

In the first session of our New Diagnosis Series, Dr. Squires joins us to discuss how Parkinson's is diagnosed, the causes of disease onset, and epidemiology of disease progression. Early symptoms, as well as both motor and non-motor symptoms of Parkinson's will also be discussed.

Date: Tuesday, February 16
Time: 11:00am – 12:00pm

Parkinson's and Treatment

Dr. Melissa Mackenzie, Movement Disorder Specialist

In this talk, Dr. Mackenzie elaborates on Dr. Squires' discussion of motor and non-motor symptoms. This session will focus on symptom management through medication, as well as advanced and alternative therapies.

Date: Wednesday, February 17
Time: 11:00am – 12:00pm

Living Well with Parkinson's: Exercise

Michelle McCarthy, Neuro Physiotherapist

Building on Dr. Mackenzie's presentation on treatment, this session will highlight exercise as

a non-pharmacological treatment for Parkinson's. In addition to outlining the benefits of exercise, Michelle McCarthy will discuss the importance of a multidisciplinary approach to managing symptoms and living well with Parkinson's.

Date: Wednesday, February 24
Time: 11:00am – 11:45am

Panel: Question & Answer Session

Movement disorder specialists, Drs. Melissa Mackenzie and Jonathan Squires, and neuro physiotherapist, Michelle McCarthy, come together for a 30-minute panel to answer your questions about being newly diagnosed with Parkinson's.

To help our panelists prepare to give you their best answers, please send in your questions ahead of time to Alana Dhillon, Education & Support Services Coordinator, at adhillon@parkinson.bc.ca.

Date: Wednesday, February 24
Time: 11:45am – 12:15pm

UPCOMING EXERCISE PROGRAMS

Hand & Dexterity Exercise Series

Join physiotherapist, Shelly Yu, for an exercise series focused on hand and dexterity challenges associated with Parkinson's disease. After the success of our Hand & Dexterity Exercise Series this summer, Parkinson Society BC is proud to bring back this exercise program for a second round! Those who joined us in July are welcome and encouraged to participate again – the benefits of exercise are best revealed when done as an ongoing practice.

Exercises in this series will target upper extremity movement, hand dexterity, grip strength, hand-finger coordination, and overall arm function. As this is a hand and dexterity class, all exercises will be done in a seated position – ideally in a chair without armrests.

Equipment needed for this exercise series includes: a small tea or kitchen towel, a small cushion/pillow, and a small elastic band or hair tie.

Dates: Thursdays, January 14, 21, 28,
February 4, 11, & 18
Time: 11:00am - 12:00pm
Cost: Free

Spread the holiday joy!

Parkinson Society British Columbia relies on the generosity of individuals, members, corporations, foundations and the dedicated efforts of volunteers.

Here are just a few ways you can support the Society this holiday season:

- In lieu of gifts, collect donations in support of the Parkinson's community across BC, or donate on behalf of a loved one.
- Participate in a local holiday fair by selling baked goods, crafts, and other seasonal treats, with proceeds supporting PSBC.
- Share your story or testimonial with the Society to help us spread the word about our programs.
- Sign up or renew your household membership with the Society for just \$25.
- Donate to Parkinson SuperWalk online through December 31st, and mark your calendar for next year's event, taking place September 11 & 12.

To learn more about how you can help, contact us at info@parkinson.bc.ca or call 1-800-668-3330.

TO VIEW OUR FULL EDUCATION EVENT LISTINGS & REGISTER ONLINE, VISIT WWW.PARKINSON.BC.CA/EVENTS

"I feel that the PSBC has done a phenomenal job in providing such substantive online support throughout this onset of COVID. Thank you so much for adjusting to these changing times."

- Gina Beddome

Thank you to our fundraisers & donors!

Full Throttle

On September 27, participants gathered in Stanley Park in Vancouver for the fourth annual Full Throttle fundraiser. The group took to the scenic Sea to Sky Highway in their cars and motorcycles, and met in Whistler for a celebratory lunch. This year's ride raised \$11,775! Thank you to organizer Jim Smerdon and his family for yet another incredible event.

RESEARCH

A new dopaminergic therapeutic target for gait dysfunction in Parkinson disease

Stiffness and freezing in place can cause falls and restrict the activities of people with Parkinson's disease. Unfortunately, the therapies available to help other motor symptoms don't usually correct these walking problems.

Neither levodopa, the medication designed to replace the loss of the brain chemical dopamine, or deep brain stimulation, a surgical treatment for Parkinson's, are very effective for improving freezing of gait.

At the University of Calgary, PhD student Linda Kim is investigating a new target for therapies to alleviate these walking difficulties.

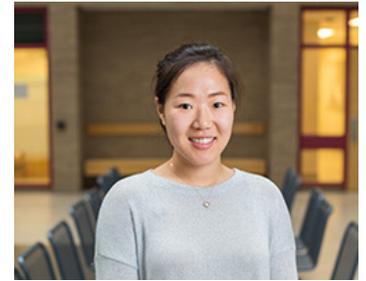
"In our lab, we're discovering a region in the brain that hasn't been studied traditionally for motor control implications," says Kim.

She's exploring a group of cells in the brain called the A13 nucleus. Using mouse models, Kim and her colleagues have discovered that when they use a type of gene therapy to target A13 in the brain and activate it using a light, mice walk better.

Kim believes A13 is an additional pathway in the brain that connects to the brain stem. By using 3-D imaging to study this region of the brain, she will learn how it delivers its information to the brain stem. She hopes this information will lead her to a way to activate A13, allowing it to take over from the parts of the brain losing other dopamine-generating cells that control movement. "It gives us an additional brain region to start thinking about when we think about freezing of gait," Kim says.

Inside A13, she hopes to demonstrate there is a reserved source of dopamine neurons that researchers could find a way to trigger, bypassing the other damaged brain circuits.

Eventually, Kim hopes A13 could become a new target for deep brain stimulation that could directly improve walking. Alternatively, physiotherapists working with people to improve their gait might be able to design exercises to target this area of the brain.



PROJECT GRANT

\$20,000 over 2 years, funded by Parkinson Society British Columbia through the Parkinson Canada Research Program

RESEARCHER

Linda Kim

INSTITUTE

Hotchkiss Brain Institute, University of Calgary

Kim pursued a career in research because she likes the hope for alternative solutions that her field provides. She focuses on research that is applicable for people. "Just having that potential to provide an alternative therapy is inspiring enough for me to keep doing the work."

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LIVING WELL: TAX TIPS CONT'D

Additional Resources

Parkinson Society British Columbia Helpsheets

Tax Tips | bit.ly/pdntaxtips

Disability Tax Credit | bit.ly/disabilitycredit

Pension Plan Options | bit.ly/CPDisabilitybenefits

Government of Canada

Disability Tax Information | bit.ly/disabilitytaxinfo

Financial Wellbeing | bit.ly/canadafinancialresources

Free Tax Clinics | bit.ly/taxclinics

Other

Access RDSP | RDSP Plan Institute | bit.ly/accessrdsp

Budget Planner | FCAC | bit.ly/canadabudgetplanner

Sources

Conference Board of Canada (2020). *COVID-19 and Uncertainty to Flatten the Curve of Economic Recovery*. Retrieved from bit.ly/3p2AzP2

Financial Consumer Agency of Canada (2019). *Setting up an emergency fund*. Retrieved from bit.ly/32mTgDn

Public Health Agency of Canada (2014). *Mapping Connections*. Retrieved from bit.ly/3p7HaYK

2021 AT A GLANCE

Parkinson Society British Columbia is pleased to announce our tentative education and support services plan for the upcoming year. More details will be provided on our website as they become available. Schedule is subject to change.

Upcoming Events

Provincial Conference

- Saturday, October 16th (tentative)

Webinars

- Speech, Swallow, & Communication Series: February
- Intimacy & Parkinson's: February
- Social Anxiety & Parkinson's: May
- The Benefits of Exercise for PD: May

Online Workshops

- SongShine with Joani: January
- New Diagnosis Series: February
- SongShine with Sharon: March & April
- Our Stories: Lives Empowered by PD: April
- Mindfulness with Dr. Judy Zhu: April
- Mindfulness and Meditation Classes: August

Online Exercise Classes

- Hand & Dexterity Series: January
- Laughter Yoga: June
- 10 Day Exercise Challenge: TBA
- Parkinson's Pilates: TBA
- Boxing for Parkinson's: TBA

Symposium Webinar Series

- March
- June
- September

Information and Referrals: Ongoing service is available by telephone or online. If we are unable to answer your questions or concerns immediately, we will research your inquiry and get back to you.

Counselling: We continue to offer free and confidential short-term counselling services to people affected by Parkinson's. These services are currently available in person, over the phone, and via video conferencing. Due to increasing demand, we extended the availability of this service from two days per week to four days per week.

Support Groups: We will continue to check in by phone and virtually with our support groups throughout the year, regular support group calls to ensure ongoing support for volunteer facilitators, to write the GroupLink monthly publication, as well as facilitator webinars/teleconferences as needed. We will also continue to foster our online support group needs and participation. We welcome all invitations to visit, however these will be virtual until further notice.

Step by Step: 12-week walking program in communities across the province. On hold until further notice.

PD Connect: We will continue to increase awareness of PD Connect, a referral program intended to help healthcare professionals connect individuals diagnosed with Parkinson's disease and their carepartners to Parkinson Society British Columbia's support services at the time of diagnosis or at any point in the disease progression.

PDLink: We will continue with this peer program that connects persons living with Parkinson's and carepartners on a one-on-one basis for support. Individuals will be connected based on similar experiences. Connections are maintained through phone and email only.

Scholarship Programs:

- Continuing Education Scholarships for healthcare professionals (6 X \$1000.00)

Online resources: We will continue to produce up-to-date resources for people with Parkinson's and their carepartners, as well as produce resources specific to healthcare professionals. We will distribute recordings of presentations and webinars through our publications (e.g, Good News, GroupLink, Pathways).

STAY CONNECTED TO THE PARKINSON'S COMMUNITY

It's that time of year again! Renew your membership with Parkinson Society British Columbia and continue to be part of our friendly, caring, and supportive community.

For only \$25, you will receive an annual membership for you and your household, valid until December 31, 2021. Reasons to renew your membership:

- **Get discounts.** Your membership provides you with great discounts on events that are not to be missed!
- **Stay informed.** Get the latest information on research, medication, caregiving, exercise, wellbeing, and nutrition when you receive our quarterly magazine, Viewpoints, and other publications.
- **Be heard.** Vote at our Annual General Meeting and add your voice to the community to garner support from donors, sponsors, and politicians.
- **Gain support.** Link to our provincial network of over 50 support groups, and speak with our knowledgeable and compassionate staff.

Get an annual membership for only

\$25

Questions? Call or email Susan Atkinson, Donor & Member Services Coordinator
604-662-3240 | 1-800-668-3330 | satkinson@parkinson.bc.ca



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