

SPECIAL NOTICE

In response to the global outbreak of COVID-19, Parkinson Society BC (PSBC) staff are working remotely until further notice. We will continue to offer programs and services in alternate formats. For the most up-to-date information, visit this web page: www.parkinson.bc.ca/coronavirus. If you have any questions, please contact us at info@parkinson.bc.ca.

UPCOMING EVENTS

- **PD Warrior 10 Week Challenge** | Tuesdays, January 4 – March 8
Learn more & join the waitlist: www.parkinson.bc.ca/pd-warrior
 - **Improv: Performance Troupe** | Wednesdays, January 12 – March 30
Learn more & register: <https://bit.ly/performancetroupepd>
 - **Drumming for Parkinson's** | Wednesdays, February 2 – March 9, & March 16 – April 20
Learn more & register: www.parkinson.bc.ca/drumming-classes
 - **SongShine with Joani** | Thursdays, February 3 – March 10, & March 17 – April 21
Learn more & register: www.parkinson.bc.ca/songshine-with-joani
 - **Tai Chi – Beginners' Progression** | Thursdays, February 3 – March 31
Learn more & register: <https://bit.ly/taichipd>
 - **New Diagnosis Workshop Series** | Tuesdays, February 8 – 22
Learn more & register: www.parkinson.bc.ca/new-dx-workshop
 - **Improv: Laughter is the Best Medicine!** | Wednesdays, February 16 – March 23
Learn more & register: www.parkinson.bc.ca/improv
 - **Ask the Expert: Intimacy and Parkinson's** | Thursday, February 24
Learn more & register: <https://bit.ly/intimacyandpd>
 - **Virtual Gardening Group** | Every 2nd and 4th Thursday, March 10 – September 22
Learn more & register: <https://bit.ly/pdgardeninggroup>
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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 Caroline Wiggins at cwiggins@parkinson.bc.ca or 1-800-668-3330 ext. 255.

TIP JAR

The Tip Jar is where we share advice from Parkinson's community members. This month, we share advice on relationships and intimacy.

- Prioritize maintaining a relationship by keeping the communication consistent. It can be something as simple as sending a one-line email by saying, "How are you doing?", "What are your thoughts?", "Tell me about your past week", or "What is new with you?"
Avoid yes or no questions and focus on asking open-ended questions. This allows the person to share more and helps to maintain relations between you and them.

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***Support the expansion of the Deep Brain Stimulation (DBS) program in BC***

In 2019, the BC Ministry of Health promised a second neurosurgeon to help reduce waitlist times for DBS surgeries. The waitlist to see Dr. Christopher Honey for initial DBS assessment is now up to four years. We need the BC Ministry of Health to follow through on their promise. TAKE ACTION and support our letter writing campaign today at www.parkinson.bc.ca/dbs.

Virtual physiotherapy service eligibility expansion

Our virtual physiotherapy service, led by PSBC's own neuro physiotherapist, Shelly Yu, launched in September 2021. We have recently expanded the eligibility requirements, and the service is now available to British Columbians who:

- have a confirmed Parkinson's/Parkinson's plus diagnosis, OR are a caregiver seeking advice on how to safely transfer/mobilize a person with PD;
- are not currently seeking physiotherapy elsewhere;
- and have limited finances and are unable to pay for physiotherapy services, OR are unable to find a suitably trained physiotherapist in their community.

To learn more about the virtual physiotherapy service, please visit

www.parkinson.bc.ca/virtualphysiotherapy.

Exercise Booklet for People with Parkinson's Disease

We recently published our new *Exercise Booklet for People with Parkinson's Disease* aimed at helping people with PD incorporate exercise into their lives for neuroprotective benefits. Digital copies are available at www.parkinson.bc.ca/exercisebooklet. For printed copies, please contact us at info@parkinson.bc.ca.

Class action lawsuit: Gramoxone® (paraquat)

Gramoxone® is an herbicide used to control weeds and grasses with an active ingredient called paraquat. It is alleged that paraquat exposure is linked to Parkinson's disease (PD). Law firm Siskinds Desmeules has filed proposed class action lawsuits on behalf of all Canadians who have been diagnosed with PD after using and/or being exposed to Gramoxone®, since July 1, 1963. To learn more, visit www.parkinson.bc.ca/gramoxoneclassaction.

Renew your membership for 2022

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

just \$25, you can sign up to get an annual membership for you and your household, valid until December 31, 2022. Learn more about becoming a member today at www.parkinson.bc.ca/membership. Do you have questions about membership? Please contact Susan Atkinson, *Donor & Member Services Coordinator*, at satkinson@parkinson.bc.ca.

COVID-19 vaccination

Throughout 2022, COVID-19 vaccines will be made available to all Canadians. Read Parkinson Society BC's COVID-19 Vaccination Statement for more information about the vaccine – including how it works, how it will be distributed, and considerations for people with Parkinson's – at www.parkinson.bc.ca/covid-vaccine.

DISCUSSION TOPIC: Intimacy & sexual health in Parkinson's

Discussion Questions

1. How has Parkinson's disease affected your ability to be intimate, as either a person with Parkinson's or carepartner?
2. How do you nurture and maintain intimacy in your relationship?

While the word "intimacy" often evokes thoughts of sexuality, intimacy is a broad concept that encompasses much more than just sexual activity. Although it is true that intimacy and sex are frequently interconnected, neither is required for the other to flourish. Intimacy is generally thought of as an emotional, rather than physical, connection, and can exist outside of romantic relationships, such as with friends and family (Levine, 2020).

There are four key types of intimacy (Levine, 2020):

1. **Physical:** this includes spending intentional, quality time together in-person, such as during a date night.
2. **Emotional:** this includes being open and honest about one's feelings and connecting through shared vulnerability.
3. **Sensual:** this includes physical touch outside of a purely sexual context, such as handholding and cuddling.

4. **Sexual:** this includes intercourse and other sexual activities.

Both intimacy and sexual activity increase relaxation, self-esteem, wellbeing, and emotional attachment between partners (“Intimacy Issues and Parkinson’s Disease 101,” 2018). Oxytocin, colloquially known as the ‘love hormone’, is released when people engage in sensual, comforting touch; it can help reduce pain and may even decrease the behavioural symptoms of dementia (“Intimacy Issues and Parkinson’s Disease 101,” 2018). Research conducted on men in the early stages of Parkinson’s disease (PD) suggests that those who maintain a healthy sex life are less likely to experience motor disability and depression, and are more likely to have a higher quality of life overall (Picillo, et al., 2019). Further studies of an elderly population show that those who regularly engage in intimate and sexual activities experience improved cognitive functioning (“Intimacy Issues and Parkinson’s Disease 101,” 2018).

Sexual health & Parkinson’s

Sexual health concerns are common amongst people with PD (Bronner & Vodušek, 2011). As sexual dysfunction may be a challenging topic to discuss, it is an often underreported, non-motor symptom of the illness that can impact quality of life for both the person with Parkinson’s, as well as their partner (Bronner & Vodušek, 2011). With adequate attention to one’s sexual health, through the application of tools, engagement with appropriate health professionals, and proper planning, a healthy sex life can be maintained.

The following is a list of the most common sexual function concerns reported amongst people with Parkinson’s; it is important to remember that everyone has a unique experience with PD, but maintaining awareness of possible symptoms opens up the opportunity for faster resolutions:

- **Decrease in libido:** studies show that approximately 65% of people with PD have a decrease in libido (Kummer, et al., 2009). Predominantly experiencing motor symptoms on the left side of the body is correlated with a greater loss of libido (Kummer, et al., 2009). Other neurological features associated with loss of libido include autonomic dysfunction, which may cause symptoms such as bladder and bowel problems, drooling,

and excessive sweating (Kummer, et al., 2009). Testosterone deficiency, which affects about 50% of men with PD, has been linked to apathy, as well as lowered sexual interest (Bronner & Korczyn, 2017); (Ready, et al., 2004).

- **Difficulties with arousal and reaching orgasm:** the majority of women with PD will experience difficulty with arousal and reaching orgasm at some point during the course of their disease progression – know that you are not alone (Bronner & Korczyn, 2017). Women with Parkinson’s experience much more anxiety and vaginal tightness during sexual encounters, both of which can contribute to decreased arousal (Bronner & Korczyn, 2017).
- **Erectile dysfunction (ED):** ED, which occurs in 60% to 80% of men with PD, is one of the most commonly studied sexual function concerns in people with Parkinson’s (Bronner & Korczyn, 2017).
- **Hypersexuality or compulsive sexual behavior (CSB):** a small number of people with PD experience impulse control disorders – CSB may be one of these (Bronner & Korczyn, 2017). These disorders can be triggered by dopaminergic medication, particularly dopamine agonists (Bronner & Korczyn, 2017).
- **Motor symptom interference:** the motor symptoms of Parkinson’s, such as tremor and lack of fine movement coordination, may cause difficulty in engaging in sensual, sexual touch (Bronner & Korczyn, 2017). Some people with PD may experience sleep disorders that can result in kicking, shouting, or punching during their dreams. Understandably, such sleep disturbances may result in partners choosing to sleep in separate beds, which can limit the opportunities for sexual activity (Bronner & Korczyn, 2017).
- **Changes in appearance and self-esteem:** hypomimia, which is a reduced ability for facial expressions, is a common symptom of PD, and may communicate an unintended message of indifference to one’s romantic partner (Bronner & Korczyn, 2017). Some individuals may also experience increased sweating and drooling, which may contribute to a decrease in self-esteem or discomfort with their appearance.

Improving sexual health & intimacy

Fortunately, there are many ways for people with Parkinson's to improve the intimacy and sexual health of their relationships, including:

- **Utilizing medication and medical treatments:** if testosterone deficiency is a concern, daily transdermal testosterone gel can quickly improve symptoms, such as loss of libido, apathy, and depression (Bronner & Korczyn, 2017). Furthermore, for individuals with PD suffering from erectile dysfunction, the drug sildenafil citrate (Viagra) has been shown to significantly improve sexual function (Zesiewicz & Helal, 2000). Lastly, if hypersexuality and compulsive sexual behavior are problems, a neurologist can work with a patient to adjust their medication.
- **Asking one's doctor for advice:** data analyzed from the US National Social Life, Health, and Aging Project, a research project that studied over 3,000 people between the ages of 57 and 85, found that only about 30% of people talk to their physician about sexual issues (Bronner & Korczyn, 2017). By opening the lines of communication with healthcare professionals, patients can get valuable advice on medical and lifestyle factors that may be having a negative impact on their sexual health.
- **Seeking the help of a counsellor or sex therapist:** the objective perspective of a professional can go a long way in helping resolve relationship issues. Parkinson Society BC offers free, confidential counselling for people with PD and their loved ones. For more information, visit www.parkinson.bc.ca/counselling.
- **Planning intimate and sexual encounters for times of day when motor symptoms are better controlled:** while penciling in time for intimacy and sex could take the spontaneity out of the experience, individuals with PD may find that such scheduling results in a more rewarding sexual encounter ("Intimacy Issues and Parkinson's Disease 101," 2018).
- **Planning sexual positions in advance of an encounter to ensure there is minimized movement when switching positions:** people with Parkinson's may struggle to frequently change positions due to the motor symptoms of PD, such as rigidity, tremor,

and bradykinesia (“Intimacy Issues and Parkinson’s Disease 101,” 2018). Some individuals report that satin sheets help make movement easier (“Intimacy Issues and Parkinson’s Disease 101,” 2018).

- **Fostering emotional intimacy outside of the bedroom:** holding hands, cooking a meal together, sharing feelings, and regularly cuddling are great ways to build emotional closeness (Gaspard, 2016). Many couples find that emotional intimacy is the foundation for a healthy physical relationship (Gaspard, 2016).
- **Reducing stress and carepartner burnout:** stress often has a dampening effect on sexuality and intimacy. Feeling overburdened can make carepartners disconnected and overwhelmed, thus further eroding the intimate relationship (Bronner & Korczyn, 2017). Stress management and reduction techniques are important, for both the person with PD and their carepartner.

Parkinson’s disease can bring challenges that impact sexual function for many people, but by remembering that intimacy can be both a physical and emotional experience, partners can foster a healthy, loving connection.

Additional Resources

Carepartner Connect: Maintaining Sexual Intimacy | Video | <https://youtu.be/004RgmVyelo>

Sexual Intimacy and Parkinson's | Helpsheets | <http://bit.ly/pdintimacy>

Small Things Often | The Gottman Institute | Podcast | <https://www.gottman.com/podcast>

Sources

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