

SPECIAL NOTICE

In response to the global outbreak of COVID-19, Parkinson Society BC 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, please visit this PSBC 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
 - **Parkinson's Pilates** | Thursdays, January 6 – 27
Learn more & register: <https://bit.ly/parkinsonspilates>
 - **Global Symposium: Environmental Pollutants & Parkinson's** | Wednesday, January 19
Learn more & register: <https://bit.ly/globalsymposiumpollutant>
 - **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
 - **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? 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. As most are off enjoying seasonal festivities with friends and family, this month, we are sharing with you a few resources that will help you make the most of your next doctor's appointment.

- **New!** ParkiTrack: <https://bit.ly/ParkiTrack>
- Preparing for a Medical Appointment: <http://bit.ly/pdappointmentprep>
- Effective Communication with Your Healthcare Team: <http://bit.ly/paceframework>

Do you have any tips or tricks that you would like to share with the PD 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.

Community Needs Survey

If you are a person with Parkinson's, carepartner/caregiver, or healthcare professional, we are seeking your feedback on our programs, services, and advocacy efforts to help guide our future priorities. Please take the survey at www.parkinson.bc.ca/communitysurvey.

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: Pain and pain-management strategies

Discussion Questions

1. If you experience pain, how does it impact your daily life?
2. What pain management strategies do you utilize, and how successful are they in helping your pain?

While pain may not be a symptom most people immediately associate with Parkinson's disease (PD), it impacts a large portion of people with PD. In fact, Parkinson's patients experience double the rate of pain when compared to those with other chronic health conditions (Wile, 2017). Research also shows that between 68-95% of people with Parkinson's will experience some degree of pain throughout the course of their illness, and for those who have had PD symptoms for less than six years, pain is the fourth most troublesome symptom. Interestingly, in a study conducted during the first COVID-19 lockdown in France, Parkinson's patients reported pain as being their number one complaint, suggesting an interplay between emotional stress and pain. Pain also greatly influences quality of life, with one study ranking it in the top five determinants (Fasano, 2021).

Many individuals may be surprised to learn that pain can actually be an early symptom of Parkinson's. For 25% of people, pain precedes a formal diagnosis (Wile, 2017). What might be rigidity and pain in a muscle as a direct result of the disease may appear to be, on the surface, a more common orthopaedic injury. It is not unusual for patients to later develop tremors on the side of the body in which they experience the most pain (Gilbert, 2019).

Levodopa, a drug commonly used to treat Parkinson's, is known to cause something called an 'On-Off' phenomenon. 'On' periods involve the patient's symptoms being under control, while 'Off' periods are times during which Levodopa is not optimized, and both motor and non-motor symptoms return. Individuals with PD feel the most pain during both early morning and nocturnal 'Off' periods (Fasano, 2021). Furthermore, peak levels of Levodopa can cause dyskinesia (rapid and involuntary movements) in some people, which may cause unwanted movements of an already-sore limb, further compounding their pain (Wile, 2017).

Parkinson's-related causes of pain

When approaching pain and considering whether or not it is Parkinson's-related, the most important question is whether or not it fluctuates.

- **Constant pain** is less likely to be directly related to PD. However, such pain can be an indirect consequence of Parkinson's, such as when a cessation of automatic gait movements, like arm-swinging while walking, causes frozen joints.
- **Partly-fluctuating pain** that gets better, but does not disappear completely on Levodopa, is likely a combination of both PD and non-PD factors.
- **Fluctuating pain** is most likely to be a direct consequence of Parkinson's. The fluctuations are caused by the effects of medication and the amount of dopamine in the brain; when the medication wears off, the pain returns (Fasano, 2021).

When dealing with fluctuating, PD-related pain, it is most likely because of:

- **Dystonia:** involuntary muscle contractions that cause twisting and often painful movements. Dystonia is a common motor symptom of Parkinson's (Fasano, 2021).

- **Rigidity:** the rigid muscles that accompany symptoms like dystonia or gait changes can cause pain throughout various muscle groups (Fasano, 2021). Sometimes, rigidity can cause permanent mechanical damage to muscles or joints, which may result in chronic pain that will not respond to Levodopa (Wile, 2017).
- **Neuropathic causes:** when there is an absence of a motor abnormality, but pain persists, the pain is likely originating from brain circuits. Such pain is often described as a burning or electrical sensation (Fasano, 2021).

Treatment of pain

There are many medical and self-management strategies available to treat pain, including:

- **Treating Parkinson's effectively:** treating the symptoms that are causing the pain is the most effective strategy for dealing with PD-related pain. It is also important to treat PD symptoms as soon as possible, because a delay in treatment may lead to biomechanical changes, like spinal cord damage or asymmetrical posture, which may later contribute to chronic pain (Fasano, 2021).
- **Avoiding painkillers:** while painkillers might seem like an obvious choice to treat pain, they are not without side effects. Opiates in particular are addictive and can exacerbate constipation that many people with PD already struggle with. Painkillers also merely cover pain without treating the underlying cause (Fasano, 2021).
- **Avoiding self-medicating with Levodopa:** sometimes people with PD may be tempted to increase the amount of Levodopa they are taking because, at first, it seems to treat their pain more effectively. However, too much Levodopa in the brain can cause an addiction to the chemical, causing dopamine dysregulation syndrome. When this occurs, patients may experience side effects like mania and dyskinesia. Furthermore, excessive use of Levodopa can cause lowered levels of B vitamins in the blood, like vitamin B12, which are essential for nerve function. As a result, these individuals may develop neuropathic pain (Fasano, 2021).

- **Utilizing alternative therapies:** Botox injections to paralyze painful muscles, medications to treat neuropathic pain (such as Gabapentin and Pregabalin), physiotherapy, and massage therapy may provide pain relief (Fasano, 2021).
- **Exercising:** gentle stretching movements like yoga and tai chi can be beneficial for people with Parkinson's, as they can help loosen muscles and promote blood flow (Wile, 2017).
- **Treating depression:** pain and depression are closely connected, as when one increases, the other may also increase. Consequently, antidepressants may be an effective tool to help battle Parkinson's-related depression (Gilbert, 2019).

While not all pain experienced by people with Parkinson's is PD-related, pain is a common non-motor symptom of the illness. Fortunately, there are many effective treatments available, so individuals may find that speaking to their neurologist is the best course of action in getting a handle on their pain (Gilbert, 2019).

Additional Resources

Ask an Expert: Pain in Parkinson's | Viewpoints Article | <https://bit.ly/viewpointspainpd>

Dystonia | Helpsheet | <http://bit.ly/pddystonia>

Parkinson's Medication Series: Levodopa | Video | https://youtu.be/HSC_vaM_z5Q

Comprehensive Care Plan Checklist | Helpsheet | <http://bit.ly/comprehensivechecklistpd>

Sources

Fasano, A. [Parkinson Society BC]. (2021, November 25). *Global Symposium Series: Dystonia and pain management in Parkinson's* [Video]. YouTube. <https://www.youtube.com/watch?v=vf-xEVIF1M>

Gilbert, R. (2019, August 27). *Is pain a symptom of Parkinson's disease?* American Parkinson Disease Association. <https://www.apdaparkinson.org/article/is-pain-a-symptom-of-parkinsons-disease/>

Wile, D. [Parkinson Society BC]. (2020, November 25). *Provincial Conference 2017: Pain in Parkinson's with Dr. Daryl Wile* [Video].

YouTube. <https://www.youtube.com/watch?v=S23qDqK7Dgs>