VIEWPOINTS

FALL 2021 A QUARTERLY NEWSLETTER BY PARKINSON SOCIETY BRITISH COLUMBIA

4 SHELLY YU ON PHYSIOTHERAPY FOR PARKINSON'S **6** EXPLORING PARKINSON'S IN WOMEN **14** COGNITIVE BEHAVIOURAL THERAPY - *AT HOME!*



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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.

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 volunteerled 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, Bereavement, Burnaby, Campbell River, Carepartner Online, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, Cranbrook, Duncan/ Cowichan Valley, Gabriola Island, Kamloops, Kelowna, Kelowna Carepartners, Kelowna West, Kootenav Lake East Shore, Langley, Langley YOPD, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Nanaimo, Nanaimo Carepartners, New Diagnosis, New Westminster, North Shore, Osoyoos/Oliver, Parkinson's Online. 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

Articles contained in *Viewpoints* are for information only. Parkinson Society British Columbia does not guarantee nor endorse any product or claim made by an author. In matters of medical treatment or therapy, patients should consult their physicians.

RESEARCH

Non-invasive ways to stimulate the brain: Transcranial Deep Brain Stimulation

When the medication to treat Parkinson's symptoms like stiffness, slowness, and tremors stops working, some people turn to deep brain stimulation. The procedure requires implanting electrodes deep in the basal ganglia region of the brain to deliver electrical pulses encouraging neurons to fire in a particular pattern.

Although the surgery is effective, it's too risky for many older people with Parkinson's who have other serious health conditions.

At McGill University, neuroscientist Matthew Krause is studying a way to deliver electrical stimulation to the same region of the brain, without the need for surgery.

Krause, a research associate, is testing transcranial electrical stimulation. This method involves attaching electrodes to people's scalps, through a tight-fitting cap, and creating an electrical field. A small batterypowered device then delivers the electrical charge to the electrodes. It creates a tingling feeling on the scalp and an electrical field that interacts with the brain's own electrical activity.

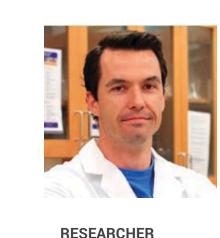
Positioning the electrodes precisely will be critical to the method's success, Krause says.

"What we're trying to figure out is how to set it up correctly to hit the kind of same deep brain structures a surgeon would target, but without drilling into your head."

Currently, only five to 25 percent of people with Parkinson's receive deep brain stimulation, and there's a long waiting list for surgery.

If Krause could find a way to encourage neurons damaged by Parkinson's disease to fire and connect with other neurons, without surgery, this new method would be accessible to many more people.

"Over the last two years, we've shown we can change how neurons fire with this transcranial stimulation," he says.



PROJECT GRANT

\$50,000 over 1 year, funded by Parkinson Society British Columbia through the Parkinson Canada Research Program

RESEARCHER Dr. Matthew Krause INSTITUTE McGill University

Commercial versions of devices that deliver transcranial electrical stimulation are already being touted as improving memory and other performance. Their results are unproven so far, prompting the need for more research.

Krause and his colleague Pedro Vieira are working with animal models to see if this method of stimulating the brain will reduce the motor symptoms of Parkinson's.

Krause was motivated to start his research by a family friend with Parkinson's. The friend, who did not want surgery, asked Krause to investigate other therapies.

"It occurred to me that what we were trying to do elsewhere in the brain would also work here," Krause says. "To the extent that this could give people back a little bit of mobility, a little bit of independence, that would make me happy."

Reproduced with permission from Parkinson Canada.

ASK AN EXPERT

Shelly Yu discusses the role of physiotherapy in Parkinson's disease management



Shelly Yu is a neuro physiotherapist based in Vancouver. She began working with the Parkinson's community in the UK at the National Hospital of Neurology and Neurosurgery. Shelly has worked in spasticity and dystonia, facial rehab, hand and vestibular rehab, and movement disorder clinics, with the latter leading her to become trained

in PD Warrior and Dance for PD. You may recognize Shelly from some of Parkinson Society British Columbia's exercise programs! Alongside her work at the Society, she is the lead physiotherapist at a private neurology clinic in the Lower Mainland. Shelly is also the Advocacy Officer at the Global Health Division of the Canadian Physiotherapy Association, working on health equity issues within Canada – specifically, access to care. Outside of her clinical practice, she is a dancer in a modern dance company and an amateur knitter!

What are some of the most common concerns you see from clients with Parkinson's disease?

Falling, and the fear of falls, is a very common concern I see in Parkinson's. There are various reasons why someone may fall or feel unstable, including: freezing, poor eyesight, dystonia and pain (especially in the feet and toes), slow movement, rigidity, and stiffness. Falls can happen anywhere, and it can cause a great deal of anxiety to feel at risk of falling. Dexterity issues (including difficulties with handwriting and opening jars), difficulty getting in and out of chairs, lack of confidence when walking, and fear of the future and loss of independence, are all factors that may further contribute to worsening this anxiety as well.

How do physiotherapists evaluate their clients? What do you look for?

We usually start with the person's main concerns, and build a picture of their general wellbeing and health condition from there. I start by asking questions about their independence to do certain activities of daily living, and their ability to participate in hobbies and maintain social circles. For the physical assessment, we usually look at posture,

walking pattern (gait), ability to pick up and manipulate small objects with hands, ability to weight-shift in different directions, ability to turn or change directions, ability to step over objects, ability to catch self when perturbed in different directions, ability to get on and off the floor, ability to get in and out of a chair, and ability to multitask.

What are some of the ways you work with clients to meet their goals?

I like to focus on educating people about the importance of exercise and self-management to maintain overall health and wellbeing. Depending on what the person's main issues are (according to what they think their issues are, and also what we find in the assessment), the exercises given will differ. For example, if someone's main issue is their bradykinesia (slowness of movement), then the exercises we tend to give are focused on big amplitude (large, wide, and sweeping movements). For tremor, the exercises are usually high-effort based, to challenge their strength and mobility. When agility and balance are the primary

concern, then the exercises we give tend to be more weight-shifting and direction-change type activities, for stability and controlled movement.

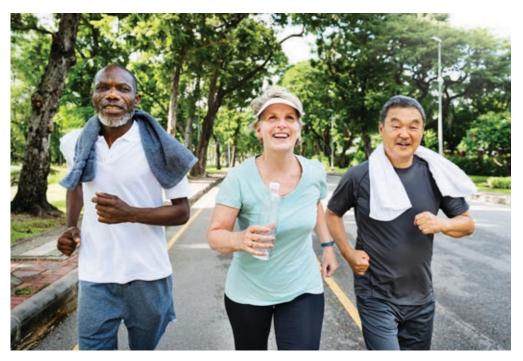
Progressive goal setting is also key: if you have a goal of being able to walk 5km, we don't just start walking 5km right away. We start small and work on taking big steps, and clearing your feet off the floor so you don't trip. Then, gradually, we work on walking 1 block, 2 blocks, 3 blocks, and so on, to build your stamina and strength until you are able to reach your ultimate goal. What we do largely depends on what the person with Parkinson's wants to achieve, and what is important to them in their lives, in addition to some things that we would like to work on for safety reasons.

What are some self-management strategies for motor symptoms in Parkinson's?

The main self-management strategy I advocate for is to find an exercise program you enjoy, and stick to

it. Exercise is so important for living well with Parkinson's. Having a consistent routine is going to make all the difference.

Other self-management strategies will depend on the type of issues you are having. If you generally feel stiff and rigid, then doing a stretching program every few hours or so will help. Since stretching will only temporarily relieve you of stiffness, doing it once a day will not be enough. Building the stretching program into your daily routine will be a good way to make sure you stick with it. For example, try doing the stretching program after every meal, or every time you return from the bathroom.



When it comes to exercise, Shelly says consistency is key.

If your issue is freezing, then finding a cue (visual, auditory, tactile, or imagery) that works for you will be important to prevent you from falling as a result of an episode. For example, you can sing a song in your head with a steady beat, and then try to step forward in time with the beat. Using visual cues on the floor to unfreeze your feet, you can step over lines such as the border between a carpet and the floor beneath to get walking again. However, before trying any cueing strategies, it is important to reset your mind: Stop trying to move and plant your feet firmly onto the floor. Take 3 deep breaths, then start again.

If your issue is dystonia in the foot and toes, then finding a way to stretch them during an episode may help alleviate the pain. Then, in between your dystonic episodes, you can try to strengthen the muscles in the foot and toes to help make them easier to control. Ultimately, for dystonia, medication would be the most valuable.

Always try to move bigger than you think you can. Step out farther, lift your feet higher off the ground, stretch your arms further, and exaggerate the swing of your arms when you walk. All of this will not only help with your walking pattern and prevent you from tripping over your feet, but you will also be working on your amplitude exercises at the same time.

What are the best forms of exercise for Parkinson's disease?

A mix of aerobic, strength, stretch, and balance training tend to be the most beneficial for Parkinson's. You ultimately need to challenge yourself and be as versatile as possible, so doing the same low-intensity routine over and over again may not be enough. You always want to work up a sweat and feel like you are exerting 70-80% of your maximum effort (of course, being wary of any health conditions that may impede your ability to exercise). A good way to test your exertion level is by feeling your heart rate increase, feeling breathless or sweaty, or feeling tired, but still be able to talk in full sentences.

Having a healthy, consistent relationship with exercise is the best way to live well with Parkinson's. If you would like to read further about exercising with Parkinson's, the Society will be publishing an exercise booklet shortly, so keep your eye out for that!

What is your advice to people with Parkinson's looking to maintain a regular exercise routine?

Don't be afraid of exercise! Tremors tend to get worse temporarily when doing intensive exercise, and this sometimes throws people off. In reality, it is a very normal sign of a good exercise program, and

CONTINUED ON PAGE 10...

LIVING WELL

Parkinson's disease in women

Women are diagnosed with Parkinson's disease (PD) at half the rate of men (Parkinson's Foundation, 2018). They also tend to experience different symptoms, medication side effects, and treatment outcomes.

Some of these differences may be due to biological factors, while others may have to do with lack of access to quality healthcare, or unconscious gender biases of healthcare professionals. Regardless, women make up a significant portion of the Parkinson's community, and it is important to understand and develop treatment plans that specifically target their unique needs.

Symptoms and disease management

Healthcare professionals must take into consideration the many ways sex and gender may play a role in their female patient's life in order to build a comprehensive care plan. Parkinson's symptoms vary so widely between individuals that it is difficult to conclude whether women experience certain symptoms and side effects more often than men do. However, research suggests that certain trends may indeed be present.

Firstly, women tend to start presenting symptoms and getting diagnosed around two years later in life than men (Case-Lo, 2018). Tremors are most commonly the first reported symptoms in women, followed by the later onset of involuntary movement (dyskinesia), depression, and other mental health challenges; this is contrasted with men, who tend to present first with slow or rigid movement (bradykinesia), and develop more cognitive issues related to Parkinson's (Case-Lo).

Levodopa, a drug commonly prescribed to treat Parkinson's symptoms, is also more likely to build up in women's bodies, as they generally weigh less than men. This often causes more side effects and fluctuations in the effectiveness of the medication.

Researchers and clinicians have also found differences between the sexes in regards to Parkinson's care and treatment. Women face more barriers to accessing healthcare overall, and those seeking a medical diagnosis tend to experience discrimination, invalidation, and prejudice when self-reporting their symptoms.

It is important to note again that each individual experiences Parkinson's in a vastly unique way. Try not to compare your experience against others, and focus on working with your healthcare team to pursue the best possible treatment options for your needs.

The potential role of estrogen

One element thought to cause some of the differences in the way Parkinson's is experienced amongst women is estrogen. Estrogen is one of the main sex hormones responsible for female physical features and reproduction. Studies have shown that estrogen may be preventative against Parkinson's (Miller et al., 2010).

Though the effect is not yet fully understood, experts believe that estrogen may play a role in protecting the brain by exerting anti-inflammatory properties. Studies have shown a connection between number



of children and later menopause – both markers of increased estrogen – with delayed onset of PD (Miller et al.). However, once the disease had developed, estrogen did not seem to make any difference on symptoms or the severity of PD. Further research is needed to discover more about estrogen's neuroprotective effects, and its potential therapeutic benefit.

Effects on pregnancy, menstruation, and menopause

As PD is more common among older populations, instances of pregnancy and PD are rare. However, so far there is no evidence to suggest that women with PD have a higher rate of birth or fetal complications (Odin, 2018). While certain symptoms of Parkinson's may affect pregnancy and vice versa, such as balance concerns, slowness of movement, fatigue, and nausea, they have not been shown to be severe or life-threatening. Additionally, common PD medications such as levodopa and dopamine have been used in pregnancies without any adverse side effects (Odin) – however, to ensure the best possible care it is crucial to speak to your physician if you are, or wish to become, pregnant.

In terms of menstruation, research has shown that over 90% of women with Parkinson's experience a worsening of symptoms before and during their period, and many report more pain and bleeding after developing Parkinson's (Odin). In these cases, healthcare professionals will seek to treat PMS symptoms first, occasionally recommending additional PD medication doses, as these medications can be less effective during menstruation (Odin). If symptoms are drastically affecting an individual's guality of life, options such as hormone therapy, surgery, or radiotherapy to induce menopause may be explored. It is important to note that common symptoms of menopause, such as fatigue, depression, sweating, and lack of sexual desire can sometimes be confused. Ensure you maintain communication with your doctor to determine the appropriate treatment for your concerns.

Effects on self-confidence and intimacy

For both men and women, Parkinson's can affect self-confidence and body image. Women especially may experience a sense of loss around their changing body – these feelings can have wide reaching effects, such as a change in how they dress or less desire for sexual intimacy. It is important to remember that sexual problems are among the most common non-motor symptoms of PD – these are valid issues that can often be addressed. Staying open with your partner and seeking help from your doctor or a sex therapist are key ways to address these common concerns.

Additional resources

Adjusting to a New Diagnosis | Video <u>https://bit.ly/newdiagnosispd</u>

Mood changes in Parkinson's Disease | Helpsheet <u>http://bit.ly/pddepressionanxiety</u>

Your Healthcare Team | Helpsheet http://bit.ly/pdhealthcareteam

Sexual Health and Intimacy in Parkinson's | Article <u>https://bit.ly/sexualhealthandpd</u>

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Do you have Parkinson'srelated legal issues?

Through a partnership with Parkinson Society BC, the law firms of Blakes, Cassels, & Graydon LLP and Hayman Faith E. Law offer free-of-charge legal services to members of Parkinson Society BC.

Blakes addresses issues such as anti-Parkinson's discrimination in the workplace, accommodations, services, or facilities that are generally available to the public; and/or denial of government services. Hayman Faith E Law advises on issues of wrongful denial of disability insurance.

For more information, please contact Jean Blake, *CEO*, at jblake@parkinson.bc.ca.



SATURDAY, OCTOBER 16

Parkinson Society British Columbia invites you to join us for an exciting opportunity to learn about recent scientific breakthroughs and disease management techniques.

Moving Forward, Together will foster an educational and inspirational space for enriching the connection between people with Parkinson's, carepartners, friends, and healthcare professionals. In light of the COVID-19 pandemic, this year's provincial conference is moving online! Featuring

presentations from prominent Parkinson's specialists and researchers across North America, this year's *Moving Forward*, *Together* will be a fully virtual experience.

The half-day event will offer three 45-minute plenary talks, with opportunities for participants to ask their questions of our expert speakers. Just like our in-person event, we will also offer guided exercise breaks.

PLENARIES

FOCUSED ULTRASOUND SURGERY & THE FUTURE OF TREATMENT

Drs. Suneil and Lorraine Kalia will be discussing the results of a world-first clinical trial on the use of focused ultrasound (FUS) for the treatment of Parkinson's disease (PD) and the potential future applications of this technology. FUS is an incisionless surgery that allows access to deep brain regions by temporarily opening the blood-brain barrier, permitting the direct delivery of therapeutics to brain regions impacted by PD. FUS is also a promising potential treatment to stop or prevent neurodegeneration. In addition, their lecture will also discuss other future treatments of PD.

SLEEP ISSUES & DISORDERS

In this lecture, neurologist Dr. Gary Leo will discuss common sleep problems that affect people with PD as well as their carepartners. Dr. Leo will explore the multiple reasons for disordered sleep and wakefulness in people with PD, discussing problems such as insomnia, excessive daytime sleepiness, and nocturnal movements. He will also highlight how recognition and treatment of these disorders can improve quality of life, as well as motor and non-motor function.

NUTRITION & THE MICROBIOME

Dr. Silke Appel Cresswell, movement disorder neurologist and researcher, will discuss the importance of proper nutrition for people living with PD. She will examine the gut microbiome, the collection of bacteria, viruses, and fungi that live in the digestive tract, and its potential role in PD. She will discuss how the microbiome may cause inflammation, which could negatively impact immune responses, damage brain cells, and cause other health problems. Dr. Cresswell will compare what the microbiome may look like in those living with PD versus a control group. Research on foods that may offer a protective benefit against PD will also be discussed.

QUESTIONS? CONTACT US!

Phone: 604-662-3240 Toll-Free: 1-800-668-3330 Email: info@parkinson.bc.ca

SPEAKER BIOGRAPHIES



Dr. Lorraine Kalia, Associate Professor in the Division of Neurology at the University of Toronto

Dr. Lorraine Kalia is a scientist at the Krembil Research Institute, University Health Network and Tanz Centre for Research in Neurodegenerative Diseases, University of Toronto. She is an associate professor in the Division of Neurology, Department of Medicine, University of Toronto. As a movement disorders neurologist, she specializes in Parkinson's disease and related movement disorders at the Morton and Gloria Shulman Movement Disorders Clinic and the Edmond J. Safra Program at Toronto Western Hospital, University Health Network.



Dr. Gary Leo, Neurologist at Columbia St. Mary Hospital in Milwaukee, Wisconsin

Dr. Gary Leo is a neurologist at Columbia St. Mary Hospital in Milwaukee, Wisconsin. He earned his undergraduate degree from St. John's University and completed his medical degree at Des Moines University. Dr. Leo completed a neurology residency at the Medical College of Wisconsin. His special interests include the evaluation and treatment of sleep disorders and Parkinson's disease. He was formally the Director of the Sleep Wellness Institute in Wisconsin, a center specializing in diagnosing and treating sleep disorders.



Dr. Suneil Kalia, Associate Professor in the Division of Neurology at the University of Toronto

Dr. Suneil Kalia is a scientist at the Krembil Research Institute and KITE Research Institute, University Health Network and an associate professor in the Division of Neurosurgery, Department of Surgery, University of Toronto. As a stereotactic and functional neurosurgeon, he focuses on the surgical management of movement disorders, epilepsy, and pain.



Dr. Silke Appel Cresswell, Movement Disorder Specialist at the Pacific Parkinson's Research Centre, University of British Columbia

Dr. Silke Appel Cresswell is a movement disorder neurologist, Associate Professor and Marg Meikle Professor in Parkinson's disease at the Djavad Mowafaghian Centre for Brain Health and the UBC Movement Disorder Clinic/Pacific Parkinson's Research Centre. She serves as president of the Canadian Movement Disorder Group, as the director of the annual National Canadian Neurology Residents Course for Movement Disorders, and is co-founder and director of the BC Brain Wellness Program as well as co-director of the Canadian Course for Ultrasound Guidance of injection therapy in dystonia.

REGISTER TODAY TO TAKE ADVANTAGE OF EARLY BIRD RATES! WWW.PARKINSON.BC.CA/MOVING-FORWARD

ASK THE EXPERT CONT'D

once the fatigue wears off, the tremor will go back to baseline again.

Keeping yourself motivated is also the best way to make sure you stick with your exercise routine. You can do this by having an exercise buddy that can join you and keep you accountable. This also makes the exercise routine more fun and sociable. Keeping an exercise diary or journal is another good way to track how often and how consistently you are exercising, and also serves as a motivator to remind you of why you started exercising in the first place. Our upcoming exercise booklet will feature all the tools you need to get started.

How can physiotherapists help people with Parkinson's get the most out of their exercise?

The best way we can help is by supporting goal setting and ensuring exercises are at the right level for you, in terms of intensity, impact, and how they help with your goals. The exercises a physiotherapist gives you should not feel easy – they should be challenging, but not impossible to do.

We can also help with identifying the underlying issues you don't see and explore the root problem. We can also cue you to move bigger, stretch further, or think of your movement in a different way so you can activate the right muscles. For example, when standing up from squats, you can think "push the floor away from you" rather than simply straightening your knees and standing tall.

The Society has various exercise classes, recordings, and helpsheets available online at <u>www.parkinson.bc.ca</u>.

What is your best advice to carepartners?

Be patient. It may be tempting to do everything for your loved one, like pulling them up out of bed, helping them walk, or finishing tasks they would otherwise do too slowly. Although some movements may be slow, it's a good idea to let your loved one finish the task themselves wherever possible. Only help if the person is unable to finish the task, and has asked for help. The more they are able to do on their own, however slow, the better!

If you are helping to transfer or mobilize someone, always use your legs and never lift with just the arms or your back, because you are likely to injure yourself.

Parkinson Society BC is launching a virtual physiotherapy service!

Parkinson Society British Columbia (PSBC) believes every person with Parkinson's disease (PD) should have access to a physiotherapist – in particular, one who is experienced in treating movement disorders and neurodegenerative diseases.

Unfortunately, physiotherapy is inaccessible to many British Columbians living with PD due to financial and/or geographic barriers. The province's Medical Services Plan only covers physiotherapy for those who are hospitalized, post-operatively, or utilizing the service at one of BC's movement disorder clinics. In-home or outpatient physiotherapy requires private pay or extended healthcare.

To increase access to Parkinson's-specific therapies, *PSBC is proud to announce the launch of a new virtual physiotherapy service on Monday, September 13, 2021.* PSBC's own neuro physiotherapist, Shelly Yu, will be accepting people with PD for phone or video-conferencing sessions. For people meeting certain criteria, this service will be available free of charge. Sessions will be available one day per week, *on Mondays (8:30am – 4:30pm).*

This service is for people with Parkinson's in BC who:

- live in rural areas of the province without adequate physiotherapy services
- have limited finances and are unable to pay for physiotherapy services
- are home-bound and unable to access in-home physiotherapy services due to geographical or financial limitations
- need specialized advice to prevent hospital admission and/or to maintain in-home safety

We also welcome carepartners in need of physiotherapy advice to safely mobilize, transfer, and/or physically assist their loved one with PD without injuring themselves.

To sign-up or learn more, please contact us at 1-800-668-3330 or info@parkinson.bc.ca.

This service is not intended to provide emergency support. In case of emergency, such as fall or injury, please call 9-1-1. Please speak to your doctor or primary care provider for advice on urgent matters.

STAY CONNECTED TO THE PARKINSON'S COMMUNITY

Get an annual membership for only

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, 2022. 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.

PARKINSON SUPERWALK

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Parkinson SuperWalk's opening ceremonies will take place on Saturday, September 11 at 10:00am! Tune in to Parkinson Society BC's YouTube and Facebook pages to watch the livestream.

Donations for this year's SuperWalk will remain open until December 31.



DONATE ONLINE TODAY AT: WWW.PARKINSON.BC.CA/SUPERWALK

LIVING WELL

Cognitive Behavioural Therapy for Parkinson's – at home!

Cognitive behavioural therapy (CBT) is a common mental health strategy that helps people find new ways of responding to situations by changing their thought patterns. CBT can help individuals reduce stress, deal with grief and loss, and cope with significant life changes.

Imagine your pattern of thought as glasses through which you view the world – thoughts can determine how you interpret, react, and behave in various situations (Davis, 2018). Thus, if you change these thought patterns, you can change your perspective and the way you respond to different life events. CBT can be used to interrupt negative thought patterns that lead to stress, anxiety, and depression, and instead teach people more beneficial ways of thinking to promote better mental health.

Mindfulness

Another common mental health strategy that deals with thought patterns is called mindfulness. There is an important distinction to be made between mindfulness and CBT. Mindfulness encourages individuals to simply acknowledge present thoughts and feelings with awareness and kindness, not engaging or judging the thoughts but simply noting their presence. On the other hand, CBT emphasizes the practice of identifying negative thoughts and reframing these thought patterns. It is a goaloriented style of therapy that requires active involvement from the individual (Davis, 2018).

CBT for Parkinson's

Maintaining your mental health is an extremely important component of managing Parkinson's disease (PD). Studies suggest that up to 50% of people with PD will experience anxiety or depression, and these challenges often have a significant impact on quality of life (Spears, 2021).

Cognitive behaviour therapy has been found to help

improve mood, reduce anxiety, and help individuals establish a more balanced outlook on life. In one study from 2019, 56% of people with Parkinson's reported improvements in core mood, anxiety, sleep, self-image, and physical symptoms when CBT was used alongside medical intervention – versus medical intervention alone, where only 8% of study participants reported improvements (Dobkin et al., 2019).

For carepartners, CBT strategies can provide skills to process and adjust to new emotions that come along with caregiving, reducing psychological stress and promoting better care for themselves and their loved one.

Overall, CBT may be a key part of a treatment plan addressing mental health concerns among the Parkinson's community.

How can I implement CBT into my daily life?

CBT can help you learn how to identify problems and harmful thought patterns more clearly, challenge assumptions and irrational thoughts, become more self-aware, and develop attainable goals. Here are some simple ways to practice CBT in your daily life:

- Become aware of unhelpful and negative thought patterns. Some of these patterns include 'all or nothing' thinking, over-generalizing, jumping to conclusions, and assigning inaccurate labels to yourself or others. Learning to identify and interrupt these patterns will allow you to move towards more beneficial ways of thinking.
- Try different exercises to examine your thoughts. You may try putting your thoughts 'on trial', by gathering evidence in support of, and against, a certain thought, and then determining if that thought is accurate and fair. Alternatively, maintain a thought record sheet or journal where you keep track of unhelpful or inaccurate responses you may have to situations, and identify alternative, or more realistic ways to interpret these events.
- Set SMART goals to make behavioural changes. SMART stands for specific, measurable, achievable, relevant, and timely. Creating SMART goals helps you identify a realistic and clear path forward towards a new behaviour or way of thinking.
- *Practice mindfulness*. CBT can be used in conjunction with a mindfulness practice.

Mindfulness meditation can teach you how to relax more easily and stay present and grounded, leading to more mental clarity and realistic thinking which can reduce anxiety and boost your mood.

Start a daily gratitude journal. One way to shift focus onto the positive aspects of your life is to start a gratitude journal. You may try making a list of everything you are grateful for, sending letters to people you appreciate, or writing down things that you are looking forward to.

Parkinson Society BC also offers free short-term, and non-crisis counselling services for people touched by Parkinson's disease. Counselling can provide you with a safe and structured environment to discuss and process emotions, learn new coping strategies, and provide you with the extra support you and your loved one(s) may need. To learn more, visit www.parkinson.bc.ca/counselling.

Additional resources

Depression & Anxiety | Helpsheet | <u>http://bit.ly/</u> pddepressionanxiety

CBT Example Sheet | Therapist Aid | Worksheet | http://bit.ly/thecognitivemodel

CBT Practice Exercises | Therapist Aid | Worksheet | http://bit.ly/practicecbt

Putting Thoughts on Trial | Therapist Aid | Worksheet https://bit.ly/thoughtsontrial

Mindfulness for Parkinson's | Video Series | https:// bit.ly/mindfulness-with-judy

Sources

Davis, K. (2018). *How does cognitive behavioral therapy work*? Medical News Today. <u>https://www.</u> <u>medicalnewstoday.com/articles/296579#how-</u> <u>does-it-work</u>

Dobkin, R. et al. (2019). Cognitive behavioral therapy improves diverse profiles of depressive symptoms in Parkinson's disease. International Journal of Geriatric Psychiatry, 34(5), 722–729. <u>https://doi.org/10.1002/gps.5077</u>

Spears, C. (2021). *Depression*. Parkinson's Foundation. <u>https://www.parkinson.org/</u> <u>Understanding-Parkinsons/Symptoms/Non-</u> <u>Movement-Symptoms/Depression</u>

SMART GOAL SETTING

S – Specific

Goals should be clear and precise, including who, what, when, where, and why.

"I will go on a walk to the park with my friend three times this week to ensure I stay active and healthy."

M – Measurable

The ability to track goals will help you stay on track and disciplined.

"I will increase my weight-lifting by two pounds."

A – Achievable

Goals should be realistic and attainable, while pushing your abilities.

"I will learn to use a new program on the computer."

R – Relevant

Ensure your goals are aligned with where you are in life, and with other goals.

"I will eat the recommended daily serving of vegetables to support my health."

T – Timely

Establish a target completion date, and set time aside to work on goals.

"I will walk three times a week, and be able to walk 5km at a steady pace by the end of the month."

Save the Date: *Global Symposium Series* Wednesdays, November 3, 10, & 24

Join us this November for Parkinson Society BC's first Global Symposium Series, featuring presentations by world-renowned Parkinson's experts. Session details and registration coming soon. Topics include:

- Pioneering Parkinson's Research from the American Parkinson's Disease Association
 Dr. Rebecca Gilbert
- Dystonia and Pain Management in Parkinson's - Dr. Alfonso Fasano
- Environmental Pollutants and Parkinson's - Dr. Baas Bloem

NEWSWORTHY

UPCOMING EDUCATION EVENTS

September Symposium Series

Parkinson's disease (PD) is a unique and multi-faceted condition. To assist in expanding your knowledge of the disease, Parkinson Society British Columbia will be hosting three webinars in this symposium series, featuring talks from the healthcare team at the Jim Pattison Movement Disorder Clinic.

Thank you to our symposium series sponsor:

abbvie

Cognitive Decline in Parkinson's Dr. Claire Hinnell, Movement Disorder Specialist

In this session, Dr. Claire Hinnell discusses the causes, assessment, diagnosis, and management of cognitive decline. This presentation will also explore signs and symptoms of cognitive change across various stages of disease progression. Co-existing conditions with Parkinson's that may worsen cognitive dysfunction will also be covered.

Date:	September 8
Time:	12:30pm – 1:30pm PT
Cost:	Free

The Impact of Cognitive Decline on Daily Living Lisa Wechzelberger, Occupational Therapist

Cognitive decline can pose significant challenges to quality of life in people with Parkinson's when it affects their ability to perform activities of daily living. In this session, Occupational Therapist (OT), Lisa Wechzelberger, joins us to discuss how OTs assess cognitive dysfunction and collaborate with patients to improve their function and skill. Cognitive rehabilitation, including some of the strategies and interventions involved, will be highlighted.

Date:	September 15
Time:	12:00pm – 1:00pm PT
Cost:	Free

Language Impairment Jamie Russell, Speech Language Pathologist

In this session, Speech Language Pathologist, Jamie Russell, will discuss communication and swallowing challenges common in people with Parkinson's, as well as general interventions and self-management strategies for patients and caregivers. This presentation will also cover strategies for working through difficulties such as following complex commands, word retrieval, and organizing thought in conversation, as well as general swallowing strategies.

Date:	September 20
Time:	11:00am - 12:00pm PT
Cost:	Free

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

Advanced Therapies Panel Series

Join this three-part panel series to learn how advanced therapies may help ease Parkinson's symptoms. Each session will feature a movement disorder specialist, person with Parkinson's disease, and carepartner, providing their expertise on Deep Brain Stimulation, Duodopa®, and Apomorphine.

Participants will have the opportunity to ask questions of the panelists – please send your questions in advance to Alana Dhillon at adhillon@parkinson.bc.ca.

Deep Brain Stimulation

Dr. Christopher Honey, Movement Disorder Specialist Leslie Davidson, person with Parkinson's Naomi Ford, Leslie's daughter & careparter

Deep Brain Stimulation (DBS) is a surgical therapy used to alleviate advanced motor symptoms that cannot be otherwise managed by medication. This webinar will explore who makes a good DBS candidate, how the procedure is performed, and outcomes to expect.

Date:	Thursday, September 23
Time:	1:30pm – 2:30pm PT
Cost:	Free

Duodopa®

Dr. Daryl Wile, Movement Disorder Specialist Chris Olsen, person with Parkinson's Harold Olsen, Chris's husband & careparter

Duodopa[®] is a levodopa/carbidopa intestinal gel used to manage advanced Parkinson's symptoms. In this webinar, Dr. Wile will cover how Duodopa[®] works, who may benefit from this therapy, and its challenges and limitations.

Date:	Friday, September 24
Time:	1:00pm - 2:00pm PT
Cost:	Free

Apomorphine

Dr. Anish Kanungo, Movement Disorder Specialist Betty Giesbrecht, person with Parkinson's David Giesbrecht, Betty's husband & carepartner

Apomorphine is a drug that acts on dopamine, administered via an injection under the skin. In this webinar, Dr. Kanungo will discuss how this drug therapy may be helpful in the management of medication off-times, which can cause difficulty with speech and mobility.

Date:	Thursday, September 30
Time:	1:30pm – 2:30pm PT
Cost:	Free

UPCOMING ACTIVITIES

Drumming for Parkinson's

This fall, Doug Pickard, REMO Health Rhythms Facilitator and Rock Steady Boxing Affiliate Owner, leads two six-week drumming classes!

Express your feelings with easy-to-follow beats and rhythms, and add drumming to your toolbox of therapies and self-management strategies! Studies have shown that the rhythmic sound and movement of drumming may help improve motor skills, mood, and cognition in people with Parkinson's disease (PD).

This series will apply the REMO Health Rhythms protocol — a holistic and evidence-based program for healthy, non-strenuous workout with a focus on socialization. One of the main goals of Health Rhythms is to understand the mind-body connection in the context of music-making. Doug and his colleagues are adapting this program to target the symptoms of PD. We welcome all people with PD and their carepartners. Registrants are encouraged to commit to the full series, as each session will build on skills and techniques introduced weekly. No musical experience is necessary.

Dates:	Wednesdays, September 8 – October 13
	Wednesdays, October 20 – November 24
Time:	2:00pm – 3:00pm PT
Capacity:	50
Cost:	Free

UPCOMING EXERCISE CLASSES

Dancing with Latin Rhythms

Explore Latin rhythm and movement in a fun and creative dance series led by Trina Frometa (Dance for PD certified). Through a joyful and non-judgemental process, dancers learn to enhance awareness of grace while focusing on PD-specific concerns such as balance, flexibility, coordination, gait, and posture. All you need is yourself and some space to move around. No dance experience is required.

Dates:	Thursdays, September 2 - 30
Time:	1:00pm – 2:00pm PT
Cost:	Free

September Challenger

Let's get moving! Kick-start the fall season with the September Challenger, a high-intensity and fastpaced exercise class suitable for those who can stand and move unassisted. PSBC's own neuro physiotherapist, Shelly Yu, will challenge your balance, coordination, and exercise stamina in this fully standing circuit class.

Dates:	Tuesdays, September 7 – 28
Time:	1:30pm – 2:30pm PT
Cost:	Free

Thank you to our fundraisers & donors!

Vernon Golf and Country Club

In honour of Mr. Rodney Vance, the Club hosted an event raising \$2,100!

St. Francis Xavier School

Thank you to students who raised \$1,000 by selling doughnuts!

Additional thanks to...

 Mighty Moose Beard Oil Co., for donating \$165 in proceeds!

SAVE THE DATE

2020 ANNUAL GENERAL MEETING

We welcome all members of Parkinson Society British Columbia (PSBC) to join us for our 2020 Annual General Meeting (AGM) this fall. Following the meeting, Dr. Andrew Howard will be joining us for a special presentation on the assessment and management of problematic anxiety in people with Parkinson's disease.

In light of the COVID-19 outbreak, this year's AGM will be hosted virtually. Stay tuned to our website at www.parkinson.bc.ca for more details. Registration will be available soon.

Saturday, November 20 Date: Time: 9:30am - 11:30am PT Date and time subject to change. Free for members. Cost: Non-members interested in attending must sign up to be a member of PSBC, and pay the \$25 annual membership fee.

ABOVE & BEYOND AWARDS

Parkinson Society BC 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 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.

At our AGM, we will recognize some of the contributions to the community based on nominations received. Please nominate someone from your community who embraces the "Above and Beyond" philosophy in their life. Nominations must be received by Friday, October 22.

NOMINATE SOMEONE ONLINE AT: WWW.PARKINSON.BC.CA/ABOVEANDBEYOND

AGM REGISTRATION IS COMING SOON. STAY TUNED AT WWW.PARKINSON.BC.CA.





