

VIEWPOINTS



FALL 2020

A QUARTERLY NEWSLETTER
BY PARKINSON SOCIETY
BRITISH COLUMBIA

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Suite 600 - 890 West Pender Street, Vancouver, BC V6C 1J9
Phone 604-662-3240 | **Toll Free** 1-800-668-3330 | **Fax** 604-687-1327
Charitable Registration Number: 11880 1240 RR0001
www.parkinson.bc.ca | info@parkinson.bc.ca

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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 benefitting 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, Cranbrook, Duncan/Cowichan Valley, Fort St. John, Kamloops, Kelowna, Kelowna Carepartners, Kelowna West, Kootenay Lake East Shore, Langley, Langley YOPD, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Nanaimo, Nanaimo Carepartners, Nelson, New Diagnosis (Vancouver), New Westminster, Osoyoos/Oliver, Parksville/Qualicum, Parksville/Qualicum Caregivers, Penticton, Port Alberni, Powell River, Prince George, Quadra Island, Quesnel, Richmond Carepartners, Shuswap/Salmon Arm, Sunshine Coast (Sechelt), Surrey, Terrace, Trail/Castlegar, Tri Cities, Tri Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Carepartners, Vancouver Downtown Working Professionals, Vancouver West Side, Vernon, West Vancouver, West Vancouver Carepartners, White Rock, White Rock Carepartners, YOPD Online

EDITORIAL STATEMENT

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RESEARCH

Validation and calibration of the PREDIGT score to predict the incidence rate of Parkinson's disease

People with Parkinson's (PD) disease rely on neurologists with clinical experience to diagnose their illness, often based largely on motor symptoms like slowness, stiffness, tremors, and difficulty walking. There are no objective medical tests to identify the disease early, or to predict who might develop it.

That could soon change, thanks in part to Dr. Juan Li's work at the Ottawa Hospital Research Institute. Li, a statistician, is testing the ability of a mathematical model called PREDIGT to differentiate between those with Parkinson's versus those without it. She'll then assess the model's ability to predict who might develop it in the future.

PREDIGT – developed by Dr. Michael Schlossmacher, a neurologist and researcher at the Institute – considers five factors, including: a person's exposure to environmental risks; genetic susceptibility; chronic tissue changes, such as inflammation and depression; gender; and age. Li and her colleagues think these factors explain the onset and potential spread of the disease.

So far, the model can successfully identify people with Parkinson's compared to people without the disease, using two carefully studied sets of data.

"Surprisingly, in our first tests the model is as good as a neurologist in accurately diagnosing Parkinson's, but we need more work," Li says.

Ultimately, Li and her colleagues want to develop a questionnaire and an online calculator tool that practitioners could use to determine the likelihood someone will develop Parkinson's during adulthood. If the model works, it could identify people before healthy persons develop any motor symptoms associated with the disease.

Before they can do that, however, Li will assess the model's accuracy and validity using a large set of data



PROJECT GRANT

\$100,000 over 2 years, funded by Parkinson Society British Columbia through the Parkinson Canada Research Program

RESEARCHER

Dr. Juan Li

INSTITUTE

Ottawa Hospital Research Institute

to see whether PREDIGT can also predict when a person who is at high risk of the illness will actually develop it.

"Prediction is more important and interesting to us," she says. "If we can tell you that you are at high risk or we can predict you may develop Parkinson's disease in five or 10 years, that's when prevention could come into play by modifying concrete risk factors in the future."

Li hopes using this tool could help people in the early stages of Parkinson's or those at higher risk of the disease access treatments being developed. For example, subjects with a high PREDIGT score might be considered suitable candidates for clinical trials.

Li, who grew up in Langfang, China, began working in the Parkinson's field after obtaining a PhD in petroleum engineering. She missed the applied mathematics field that was her first love during her undergraduate years and wanted to work on something meaningful – which led her to the Parkinson's work in Ottawa.

While working with Dr. Schlossmacher, she met people with Parkinson's and their families.

"A lot of people have a lot of knowledge about this disease and interest in our model – so that made me feel really happy. This is the perfect chance for me to do something that I really care about."

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ASK AN EXPERT



Courtney Doherty discusses stress management

Courtney Doherty, MCP, RCC, is a clinical counsellor with Parkinson Society British Columbia (PSBC). The Society offers free, short-term, confidential, and non-judgemental counselling services for people touched by Parkinson's disease (PD).

Counselling provides a safe and structured environment to discuss challenges, process emotions, and provide you with the extra support you and your loved ones may need. Our counsellors have experience working with people with Parkinson's, and their carepartners and family members. They are able to help in dealing with a combination of issues including coping with a diagnosis, life transitions, grief and loss, depression, anxiety, and stress.

Courtney completed her Masters of Counselling Psychology at Adler University in Vancouver. She has been working as a Registered Clinical Counsellor (RCC) with the British Columbia Association of Clinical Counsellors for over 5 years, and has a part-time private practice. Courtney's father was diagnosed with PD over 15 years ago, and successfully underwent Deep Brain Stimulation surgery. Believing that every individual has the potential to lead a happy and fulfilling life regardless of challenges faced, she brings a unique perspective and skill set to PSBC.

What exactly is stress?

Stress is the body's natural response to danger. Our ancestors were faced with dangers in their environment and developed an effective response in order to survive as a species. This response includes a rapid series of physiological and psychological reactions that helps us decide whether to stay and fight, or run away to safety. This is known as the "fight or flight" response.

Fight or flight prepares the body to react to stress. When faced with danger, the sympathetic nervous system is activated, causing adrenaline and cortisol to be released into the blood stream. These hormones

cause the heart rate and blood pressure to increase, directing blood to our muscles to increase strength; they also cause our pupils to become dilated so we can better see our surroundings, and our breathing to become rapid and shallow, boosting oxygen intake in preparation for a fight or flight.

This physiological response has helped humans successfully overcome many dangerous and threatening situations. Today, however, we are faced with different kinds of stressors than our ancestors once faced. This might include real physical threats (jumping out of the way of a moving vehicle), or perceived psychological threats (preparing for a deadline), but our brain and body still respond in the same way.

What is the difference between good and bad stress?

There are two kinds of stress: "bad" stress (known as *distress*), and "good" stress (known as *eustress*). We often talk about distress when referring to the experiences we face, but it is important to recognize that some things that are viewed as good or positive can also be stressors, like having a baby, buying a house, or getting a promotion at work. The more overall stress that we experience, the more taxing it is on our body and mind.

What are the effects of stress on one's mental health?

A certain amount of stress is a normal part of life and can actually be beneficial for things like completing tasks or meeting deadlines. However, long-term or "chronic" stress can be harmful, and can lead to an increased risk for physical and mental health issues. If we are faced with chronic stress, our nervous system is constantly being activated, and this may make it difficult for us to return to a state of rest. If stress piles up, we can become overwhelmed and feel unable to cope with anything, which is commonly referred to as "burnout." If we continue on without doing anything about the stress, it can lead to further health problems, including hypertension, heart disease, and anxiety.

How can stress manifest in the body?

Things like muscle tension, sleep problems, digestive issues, inflammation, anxiety, and low mood are among

some of the most common ways stress manifests in the body. If the “fight or flight” response is frequently activated, the body will eventually have difficulty returning to a normal, balanced state. We therefore want to deactivate the sympathetic nervous system and activate the parasympathetic nervous system (PNS), commonly referred to as the “rest and digest” response. One of the easiest ways to activate the PNS is to practice deep diaphragmatic breathing (slow and deep breathing through your diaphragm). Other ways to activate the PNS include grounding exercises like naming 5 things you see in front of you, physical exercise, being out in nature, and practicing mindfulness and other relaxation techniques.

How can stress impact Parkinson's symptoms?

Stress can make Parkinson's symptoms worse, because it forces the body to prioritize basic functions in an attempt to cope. We might think we are managing our stress just fine, but stress can slowly accumulate, leading to an overload on our nervous system, which affects our overall health in the long run. Stress can lead to increased tension in muscles, inflammation in our cells, lack of sleep, increased pain, and digestive issues. Stress can also have a significant impact on our mental health leading to increased symptoms of anxiety and depression. These common reactions to chronic stress are also symptoms that people with Parkinson's might already be facing, so it is imperative that we manage our stress before it manages us.

What about stress in carepartners?

Stress in carepartners is equally important to address, since caring for someone is a very demanding responsibility. Carepartners often fall into the role of caring for their loved one – a role they likely did not expect, and for which they may feel unprepared. This may come with a variety of emotions like anger, grief, and sadness, along with physical and psychological stress. It is important to recognize and be honest about the amount of responsibilities we can handle as carepartners, and to reach out for support before it becomes overwhelming.

It is important for carepartners to realize that they cannot care for another person if they are not caring for themselves first. Think of the age-old airplane analogy of putting on our own oxygen mask before we can assist others. We must think about how we can care for ourselves throughout the day to ensure that we avoid burnout. The concept of self-care is often

misunderstood; it does not need to look like a bubble bath with candles. It can be much simpler. Self-care involves intentionally planning to do something that recharges your batteries. This can mean taking five minutes to appreciate your morning coffee, listening to a song that makes you feel good, or writing down three things for which you are grateful. We must deliberately practice caring for our needs throughout our day in order to take care of the needs of others.

What are some good ways to self-manage stress?

- Practice deep breathing, mindfulness, and grounding exercises.
- Seek psychological support through counselling.
- Reach out to loved ones.
- Focus on what you can control.
- Practice gratitude (name things you are grateful for).
- Exercise in a sustainable way (10-minute walks vs. 30-minute runs).
- Eat a balanced, nutrient-dense diet.
- Get adequate sleep in a good sleep environment (tidy, dark, distraction free).
- Take medications on time, and as directed by your medical practitioners.
- Self-care (in a simple, deliberate way) – enjoying good music or food, enjoying the view, looking at a calming photo.

How can seeing a counsellor help with stress?

Counselling can help reduce stress in many ways. It can help you identify factors in your life that cause you stress, and develop coping strategies to handle those stressors in healthy way. This might include things like making schedules to prioritize self-care, teaching you mindfulness and relaxation techniques, and providing you with skills to recognize and reframe negative patterns in your life. Counselling might also help you to realize different goals and motivate you to implement positive change. It can help reduce feelings of guilt and shame for carepartners who avoid caring for themselves. Counselling can also be a safe environment to talk about things that might be weighing on you emotionally, or to simply gain another perspective.

Parkinson Society BC offers free, short-term counselling for anyone affected by Parkinson's disease. To learn more about our counsellors and how they can help you, visit www.parkinson.bc.ca/counselling or contact Courtney at counselling@parkinson.bc.ca.

LIVING WELL

Improving balance and preventing falls

Parkinson's disease (PD) affects the parts of the brain controlling balance and coordination. As a result, balance and coordination adjustments that were once automatic now require conscious effort. Additionally, some drugs used to treat PD can lower blood pressure, causing a feeling of faintness when getting up from a sitting or lying position (called orthostatic hypotension). Difficulty with balance and/or low blood pressure can increase the risk of falling and bone fractures, both of which can be serious.

Evaluating fall risk

Falls can be caused by many factors, both relating to your physical health and fitness, and your environment. Some of the fall risk factors common in Parkinson's include:

- advanced or severe symptoms
- cognitive changes
- fatigue and sleep disorders
- freezing (particularly freezing of gait)
- depression, stress, and anxiety
- fear of falling
- medication use, and medication interactions (causing side effects or "off" periods)
- reduced leg strength, and trunk rigidity
- poor mobility, bradykinesia (slowness), and dyskinesia (involuntary movement)
- urinary incontinence and urgency (particularly at night, called nocturia)
- changes in posture, or postural instability
- acute illness with Parkinson's
- difficulty turning, changing direction, backing up, and moving around obstacles
- home and community hazards

Although many of the factors above cannot be changed, it is possible to work on improving mobility and balance, and remove hazards from your environment to avoid falls. To determine your

individual risk factors, contact your healthcare team or your local home and community care office to arrange an assessment with a physician, physiotherapist, occupational therapist, or other healthcare professional.

During a falls risk assessment, you may be asked to perform small tests, such as (PSBC, 2019):

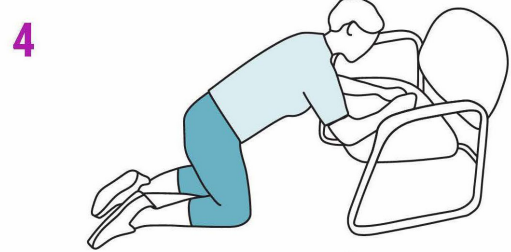
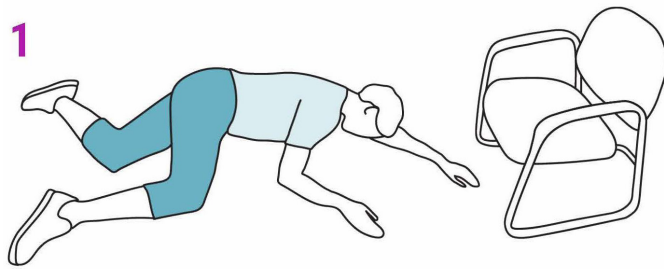
- multi-tasking, especially while walking
- getting up and down from the floor
- maintaining balance when nudged in various directions
- turning in a small space
- picking objects up from the floor
- stepping backwards safely

Minimizing risk

Here are a few suggestions on how to avoid falls and manage balance problems:

- Use cueing strategies to overcome freezing of gait.
- See a clinical counsellor to discuss mental health concerns or fears of falling.
- Exercise to improve your mobility, leg strength, posture, agility, and walking.
- Speak to your healthcare team about incontinence and nocturia, or seek referral to a continence or pelvic floor therapy service.
- Have your blood pressure checked frequently to ensure it is not too low.
- Remove throw rugs and low-lying obstacles from pathways inside and outside your home.
- Avoid using stepladders and stools.
- If you walk with a cane, use one with a large base, or a walker with brakes. Get professional advice before making any major purchases.
- When walking, stand as straight as you can, and walk with your feet a little wider apart than normal.
- Wear comfortable shoes with good arch supports. If you shuffle, avoid shoes with rubber or crepe soles.
- Pay careful attention to changes in ground surfaces (eg. curb to pavement, or carpet to bare floor).

Some balance problems, like postural instability, can be more complex and require assessment by a physiotherapist. Exercises that may be prescribed for postural instability may be multidirectional swaying and stepping exercises.



Recovering from falls

If you fall, stay calm, and remain where you are. Take a moment to conduct a body scan (mentally scan and feel from head to toe) to see if you are hurt anywhere. If you are hurt, do not move, and call for help. If you are not hurt, then you can try getting up from the floor using the technique below, with help from a chair or something else sturdy. Only do this if you are sure you are not hurt and can get up by yourself. If you need help getting up from the floor, do not attempt this without assistance, as you could fall again.



If you need assistance getting up from the floor, or there is nothing sturdy to hold on to, you can use the same techniques as above, performing steps 4 through 6 with a person in place of a chair, given that the person assisting feels they are able to do so.

Balance checklist

Balance and good posture can work together to improve your activities of daily living. When your body is correctly aligned, movement is more efficient and stable. To establish good posture:

1. Stand with your back against a wall, your feet flat on the floor, and your heels approximately 3-4 inches or less from the wall.
2. Hold your head erect, chin parallel to the floor, and your vision focused on a target at eye level.
3. Relax the arms and shoulders.
4. The buttocks, shoulder blades, and, if possible, the back of the head should be touching the wall. Focus on keeping chin parallel with the floor and eyes on a target.
5. Evenly distribute weight throughout feet, front to back, and side to side.
6. Pull your abdominals in, and lift your chest.
7. Hold position for 15 to 30 seconds, and then relax.
8. Repeat the above directions 2-3 more times.

Sources

Parkinson Society BC (2019). *Naomi Casiro Discusses Balance & Falling in Parkinson's*. Viewpoints Fall 2019. Retrieved from: <https://bit.ly/vptsbalancefalling>

LIVING WELL

Brain games for cognitive health

Exercise is a beneficial way for people with Parkinson's disease (PD) to manage motor symptoms, but did you know that it is also important to keep your brain active? People with PD often experience cognitive changes, including difficulties with attention, focus, memory, problem solving, and language. These changes are associated with a drop in the level of dopamine, along with several other chemical messengers in the brain, known as neurotransmitters. There are certain activities that you can do to maintain and improve cognitive health, such as brain games, socialization, and creative hobbies, which can all boost the production of neurotransmitters and hormones important for healthy brain function. Whether you are a person with PD, or a carepartner, these mental stimuli can help you flex your 'thinking muscles' and support your overall wellbeing.

Play brain games

Brain games are an easy, accessible, and fun way to exercise your brain. These games include any activity that stimulates your thinking, such as word puzzles, jigsaw puzzles, chess, sudoku, riddles, trivia, and computer games. Research has shown that these types of activities help sharpen brain skills that can often be affected by Parkinson's, such as focus, decision making, and memory. Alongside regular physical exercise, these brain activities can also help build the "cognitive reserves" in your brain, which contribute to resilience and quick-thinking (Harvard Health, 2019).

Check out the following brain games:

- SuperBetter is an online and mobile game that uses game play to build resilience. www.superbetter.com
- Luminosity is an online and mobile platform that takes scientifically-validated tasks and turns them into fun games. www.luminosity.com
- Brain Yoga Brain Training Game is a mobile app featuring puzzles that train memory, vocabulary, numeracy, and spatial awareness. Find it on the App Store on iPhone or iPad, or the Google Play Store for Android devices.

- Games for the Brain is an online platform with quizzes and memory games to help train your thinking. www.gamesforthebrain.com

Engage socially

Socializing is another key way to maintain your cognitive health and avoid feelings of loneliness or isolation. It makes us strong and resilient in the face of adversity, and generates dopamine which can help boost happiness and improve cognition (Cohut, 2018). Research has shown that when we interact with others, we train our brains — social contact and close relationships are associated with better memory and mental agility (Cohut, 2018). While the way we communicate may look a little different during COVID-19, you can stay connected to family and peers through phone or video calls, online support groups, or online activity classes.

Visit www.parkinson.bc.ca to find information on support groups and online workshops, like drumming or singing classes, that can help you stay connected and improve your communication skills and brain health.

Get creative

Creative activities are not only fun, but they have also been shown to benefit mental and physical health. Like socialization, creative engagement produces the neurotransmitter dopamine, reducing stress and promoting happiness (Stahl, 2018). Furthermore, studies have shown that getting creative helps individuals find purpose and sharpen their senses. Things like painting, gardening, woodworking, and other activities can strengthen problem-solving and critical thinking skills often affected by Parkinson's (Stahl, 2018). Playing an instrument can improve cognitive function by increasing communication between your left and right brain (Stahl, 2018). Regardless of what you choose to do, being creative is a notable way to reduce stress, find purpose, and improve brain health.

Sources

- Cohut, M. (2018). *Socialization: How does it benefit mental and physical health?* Retrieved from <https://bit.ly/32WjIEA>
- Harvard Health Publishing. (2019). *The thinking on brain games*. Retrieved from <https://bit.ly/2EqqBV8>
- Stahl, A. (2018). *Here's How Creativity Actually Improves Your Health*. Retrieved from <https://bit.ly/3iXkXcn>

PARKINSON SUPERWALK®

Thank you to everyone for your enthusiastic participation in, and generous donations to, the 30th annual Parkinson SuperWalk. Although we could not be together in person this year, we were delighted to see support from across the province, as so many of you gathered your friends, families, and colleagues to keep the SuperWalk spirit alive! This year, your incredible support has helped to raise over **\$233,000...** and counting. These funds will allow the Society to expand its reach, providing advocacy, programming, support services, and contributions to research for the 13,000 British Columbians living with Parkinson's, and their carepartners and families.

Stay tuned to our website and the next issue of Viewpoints, where we'll be announcing our top fundraisers and teams!

If you couldn't join us this year, it's not too late to help us make a difference. Donations for this year's SuperWalk will be accepted through December 31st, 2020!

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

CAREPARTNER'S CORNER

Carepartner respite and self-care during the COVID-19 pandemic

The COVID-19 pandemic has introduced a number of challenging new realities in our society. For many, it has caused major disruptions in daily schedules, heightened feelings of stress and anxiety, and made it more difficult to access necessary resources. For caregivers, these impacts may hit especially hard as they navigate the pandemic alongside existing responsibilities of caring for their loved one(s). With many businesses closed and physical distancing guidelines in place, caregivers may not have the same opportunities as they did before to enjoy leisure time, social outings, or time away from their caregiver role. The pandemic has left carepartners especially prone to losing sight of their own needs and forgetting to prioritize self-care. Like their loved ones, it is essential for caregivers to ensure they are receiving the support they need to live a healthy, happy life.

Respite resources

Respite includes any form of short-term relief from care duties, allowing carepartners to take a break from their role and enjoy some downtime. There are several different types of respite, one being informal arrangements with family and friends. Close family members and friends may be willing to help by doing some household chores for you, such as grocery shopping or cleaning, or they may be able to take your loved one on an outing or care for them for a period of time, allowing you some time for yourself.

Formal services such as in-home assistance can offer a similar option, where professional nursing or care staff will come to your home to assist with medical requirements or perform care duties for your loved one. Adult day programs are community-based recreational programs offered to people who need extra care or support. These half-day or day-long programs may focus on supporting your loved one with exercise, toileting, and eating and mobility issues, while providing time away for you. If you experience injury or illness, short-term residential care (less than

3 months) is another respite option where your loved one can receive temporary assistance.

Taking advantage of respite care and professional support can help facilitate independence and healthy boundaries between you and your loved one with Parkinson's disease. They can help you manage your time, stay positive and energetic, and support your ability to continue providing excellent care.

Mental health & self-care

During these unprecedented times, it may be difficult to access support services due to long waits, limited capacity, and strict safety protocols. It can also be challenging to arrange for informal support from family and friends while practicing social distancing. As a result, many carepartners are now facing the additional stress of managing the majority of their loved one's care on their own, with limited access to respite. To help you better manage your caregiving duties, it is important to first manage your mental health, and establish a self-care routine and healthy coping strategies.

Acknowledge change

As a caregiver during this time, start by acknowledging new challenges and taking time to process them. While difficult, being open to change can help you stay positive and find joy in the things you are still able to do with your loved one. Reach out to friends or family who may be able to listen or lend a helping hand. Try to be kind and non-judgemental, and speak to yourself like you would speak to a friend – your job can be both challenging and profoundly rewarding.

The Parkinson's journey is made up of many incremental losses that must be grieved. These can include things like future plans, independence, physical abilities, or hobbies and interests. Carepartners need to be prepared to acknowledge and accept these losses, and support their loved one in adapting to the changes in their life caused by Parkinson's. During this pandemic, you may also be faced with temporary losses, like being disconnected from your friends or support group; any loss, no matter how big or small, should be acknowledged and accepted as part of a healthy coping strategy.

Acceptance can be a painful process. Many approach difficult life changes by focusing on how to move forward, without taking the time to work through

their emotions. If these emotions are left to build over time, they can have a significant impact on one's mental health. Mindfulness can be a good tool for carepartners looking to work on acceptance. All you need to practice mindfulness is to bring your attention to the present moment, and view it objectively, without judgement. This includes allowing negative or painful thoughts to cross your mind, and simply acknowledging and accepting them.

Prioritize your needs

Things like sleep and good nutrition are vital to maintaining your physical and mental health. While it is easy to become focused on the medical needs of your loved one, it is also important that you are keeping up to date with your own health and medical appointments (yearly physicals, vaccinations, mammograms, etc.). Another way to avoid feeling overwhelmed with responsibility is to make daily to-do lists, prioritize and break down tasks, take breaks, and reward yourself when the job is done. Fulfilling these basic needs and organizing your schedule ensures you stay healthy and positive.

It is also valuable to carve out and schedule time during the day to do things you enjoy. Even if you feel guilty about taking this time out for yourself, understand that it is a crucial aspect of reducing your stress levels and maintaining a life outside your role as a caregiver. Taking time to relax, decompress, and have fun will give you more energy and enthusiasm to continue providing the best possible support to your loved one.

Activities like meditation and breathing exercises can help decrease heart rate and blood pressure, alleviate stress, and increase optimism and compassion. Using a journal or sketchbook may help you express your experiences in a creative way and facilitate therapeutic release of anxiety. Exercising is a great way to maintain your physical health while releasing endorphins that will have a positive effect on your mind and body. Finally, don't forget to laugh! Though it sounds simple, taking time to laugh at your favourite sitcom or comedian has been shown to soothe tension, improve your immune system, and increase personal satisfaction (Mayo Clinic, 2019).

Socialize & communicate your experience

Socialization is another key aspect of good health

and wellbeing. You may have heard that humans are naturally social beings – the encouragement and comfort we find in social interaction makes us resilient and strong (Cohut, 2018). Find someone you trust to talk openly and honestly about your experiences with. During COVID-19, this may look like a Zoom meeting, a phone call, or joining Parkinson Society BC's PDLINK Program. If you feel comfortable, get outside for a physically-distanced walk with a friend. Consider joining an online caregiver support group to spend time with peers facing similar circumstances. Support groups can be an opportunity to ask questions, discuss concerns, find more resources, and connect with others. These groups are a great reminder that you are not alone in your journey.

Additional Resources

Please contact your local health authority's Home and Community Care office for more information on home health services and community programs in your area:

Fraser Health | www.fraserhealth.ca

Interior Health | www.interiorhealth.ca

Island Health | www.viha.ca

Northern Health | www.northernhealth.ca

Providence Health | www.providencehealthcare.org

Vancouver Coastal Health | www.vch.ca

Parkinson Society BC Resources

PDLINK | www.parkinson.bc.ca/pdlink

Support Groups | www.parkinson.bc.ca/groups

Counselling | www.parkinson.bc.ca/counselling

Caregiving Resources | <https://bit.ly/psbccaregiving>

Home and Community Care Services for People with PD and Carepartners | <https://bit.ly/psbchomecare>

Other Organizations

BC211 Safe Seniors, Strong Communities | www.bc211.ca

Canadian Mental Health Association | www.cmha.ca

Family Caregivers of BC | www.familycaregiversbc.ca

Sources

Cohut, M. (2018). *Socialization: How does it benefit mental and physical health?* Retrieved from <https://bit.ly/32WjIEA>

Mayo Clinic (2019). *Stress relief from laughter? It's no joke.* Retrieved from <https://mayoclinic.org/35X33mi>



Pushing limits and raising awareness

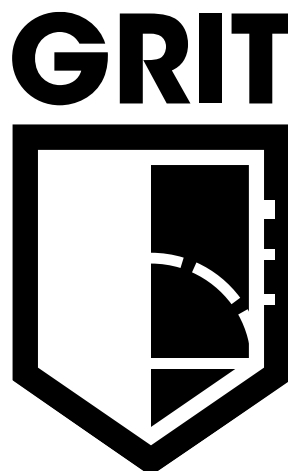
Norm Plumb was diagnosed with Parkinson's disease (PD) six years ago. At first, the diagnosis was surreal – to his family, Norm was the life of the party and things didn't seem to affect him like they did other people. Those early years brought challenges for the family as they learned how to support Norm and each other through the onset of new and difficult symptoms.

Last year, Norm's sons, Doug and Colin, decided they wanted to raise awareness for Parkinson's and catch people's attention in a big way. From a young age, Norm instilled in his sons a love of sports, leading Doug and Colin to become heavily involved in basketball and coaching youth teams. As lifelong athletes, they view exercise as a positive outlet and an opportunity to spend intentional time with their father. Out of this love of physical activity and the desire to make an impact, the Grit Day fundraiser was born.

Grit Day is a full-day affair, testing the physical and mental 'grit' of participants while raising awareness and funding to improve the lives of those affected by PD.

During the event, participants complete intense exercises all within a 24-hour period, including a half marathon, climbing the Grouse Grind, 500 push-ups, a 10-minute plank, and more – if you can believe it!

This year, Doug and Colin hoped to raise \$30,000. They surpassed their goal to raise a total of \$45,306.



\$45,306

Our inspiration was seeing the resilience that our father embodied through his daily fight against the disease," Doug explains, "we thought by doing something that pushes the limits of our body, something most would deem as impossible, it would turn into more awareness and funds raised."

Grit Day is definitely demanding – however, Doug firmly believes that pushing your limits has a positive effect on mental and emotional health. Even more so, he says the people and support from the community make the day worth it. His friends, family, and even the families on the team he coaches come out in support of the event. "It's inspiring and uplifting, without question," says Doug. Grit Day represents the grace and strength of the Parkinson's community, and encourages others to get involved in something bigger than themselves.



Photos courtesy of Doug Plumb.

NEWSWORTHY

UPCOMING WEBINARS

Exploring the Role of Cannabis in Parkinson's

Dr. Jean Paul Lim, a complex care specialist, is dedicated to studying the benefits and side effects of medicinal cannabis use for a variety of conditions. In this webinar, he joins us to discuss real-world data on the potential ways that cannabis may be used to managed Parkinson's symptoms.

Date: Tuesday, October 20
Time: 1:00pm - 2:00pm
Cost: Free

Ask the Expert: Dementia in Parkinson's

In this webinar, Dr. Naaz Parmar will provide an understanding of dementia, its different subtypes, and how they can affect a person with Parkinson's. This presentation will also provide an overview of treatment options, including lifestyle changes and medications.

Date: Wednesday, October 28
Time: 1:00pm - 2:00pm
Cost: Free

Ask the Expert: Medication Q&A

Bring your questions about medications as pharmacist Amy Tran joins us to answer your questions and to provide resources to empower you to get the most out of your treatment.

Date: Friday, October 30
Time: 1:00pm - 2:00pm
Cost: Free

Gut Health & Parkinson's Series

Dr. Edward Ishiguro, Professor Emeritus in the University of Victoria Department of Biochemistry & Microbiology, joins us in this webinar series to discuss the link between the gut and Parkinson's.

Dates: Mondays, November 9 & 16
Time: 1:00pm - 2:00pm
Cost: Free

UPCOMING EXERCISE PROGRAMS

Thawing Out: Exercises for Freezing

Join us in this online exercise series, as Parkinson Society BC's own neuro physiotherapist, Shelly Yu, leads us through 4 weeks of targeted exercises to improve motor patterns. The class will start in a sitting position, and move to standing. Please note that there will not be an option to remain seated the entire class, due to the nature of exercises targeting the feet and walking. Participants may wish to have a loved one nearby to ensure their safety. Proper footwear is recommended.

Dates: Thursdays, October 15, 22, 29,
& November 5
Time: 11:30am - 12:30pm
Cost: Free

Dance the Holidays: Nutcracker Repertoire

In this series, Shelly Yu will lead participants into a modified repertoire from the classic Nutcracker ballet. Dances include the famous Sugar Plum Fairy dance, Waltz of the Snowflakes, Mouse King Battle, March of the Toy Soldiers, Mother Ginger, and others.

Dates: Thursdays, November 12, 19, 26,
& December 3
Time: 11:30am - 12:30pm
Cost: Free

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

Thank you to our fundraisers & donors!

UBC PATHS

Thank you to UBC's Parkinson's and Alzheimer's Targeted Hope and Support (PATHS) club for their ongoing support. This summer, they raised \$480!

Grit Day

Thank you to Doug and Colin Plumb for partnering with the Society for their second annual Grit Day fundraiser! On Saturday, August 29, participants came together to complete a series of extreme physical challenges in just 24 hours. The event raised over \$45,000!

ADVOCACY UPDATE

Allied Healthcare Professional Funding

Parkinson Society British Columbia (PSBC) aims to be an effective lobbyist for issues important to the Parkinson's community. With the grassroots support of our advocacy networks, we have influenced the Ministry of Health to increase funding and access to crucial Parkinson's disease (PD) treatments, like Duodopa® therapy and Deep Brain Stimulation (DBS) surgery.

In the past year, the Society focused its efforts 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 with Parkinson's disease. By allowing people to live independently for longer, this 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.

Location remains a primary barrier British Columbians face in accessing Parkinson's-specific care. The majority of specialists treating neurodegenerative disorders are located in the Lower Mainland, forcing patients to travel from across the province. Funding local movement disorder clinics and other healthcare providers is an important first step to bringing specialized care closer to home for thousands of families impacted by PD.

Interior Health

The Central Okanagan has the highest crude prevalence rate of Parkinsonism in the province — increasing approximately 17% in the past five years.

To support our community in the Okanagan, we are providing incentive funding for several AHCPs through the Okanagan Movement Disorder Program. This funding, in the amount of \$445,000, will support a part-time physiotherapist, a part-time speech-language pathologist, and a part-time social worker, over five years. Funding for these positions will transition into the Health Authority's base budget in years four and five.

Island Health

There are roughly 2,650 people with Parkinson's living in the Vancouver Island Health Authority region. A partnership between Island Health and PSBC has allowed for expedited hiring of a full-time speech-language pathologist, bringing better care to people affected by Parkinson's disease in the region.

The Society will provide funding, totalling \$498,000 over five years, for this position. Funding will transition into the Health Authority's base budget in years four and five.

Next steps

Increasing access to AHCPs across the province remains one of the Society's top advocacy priorities. Alongside providing direct funding, we are also committed to influencing policymakers to implement long-term supports for people with Parkinson's and their families, wherever they may live. Access to Parkinson's-specific therapies for those with advanced symptoms also remains extremely limited.

Duodopa® and DBS can alleviate pain and severe disablement in people with PD, but waitlists are long, and only a small number of people can receive these treatments each year. In our submission to the Select Standing Committee on Finance and Government Services this June, PSBC recommended supporting individuals to access DBS in other provinces until capacity improves in BC, and removing the cap on the number of individuals who can receive Duodopa®. This will be the platform for our advocacy efforts this fall, after the provincial election. You can help by asking the candidates in your riding what their party will do to increase care for people with Parkinson's.

Do you want to support our advocacy campaigns? Contact Jean Blake, CEO, at jblake@parkinson.bc.ca to learn about how you can get involved. Our advocacy efforts are funded by the generous support of our donors and members. Help us make a difference by donating online today at www.parkinson.bc.ca/donate.

CORRECTION

In our 2019 Annual Report, included in the previous issue of Viewpoints, John Hougan was not listed as one of our Board Directors, and Michelle O'Connor was listed under her maiden name, Bourbonnais. These errors have now been corrected online.

SAVE THE DATE

2019 ANNUAL GENERAL MEETING

We welcome all members of Parkinson Society British Columbia (PSBC) to join us for our 2019 Annual General Meeting (AGM) this fall. 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.

Date: Saturday, November 21

Time: 9:30am – 11:30am

Cost: Free for members.

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 opportunities and foster relationships they had never imagined possible before their diagnosis.

At our upcoming 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 Wednesday, October 21.

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

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



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