

VIEWPOINTS

A woman with grey hair, wearing a white jacket and a green apron, is watering tomato plants in a garden. She is holding a large, light blue metal watering can. The plants are lush green with several red and yellow tomatoes. The background shows a wooden fence and a building.

A quarterly newsletter for the
Parkinson's Community of British Columbia

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2018

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OUR MISSION

Parkinson Society British Columbia exists to address the personal and social consequences of Parkinson's disease through education, outreach, scientific research, advocacy and public awareness.

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Your support is essential!

PSBC would not exist without the generosity of its members, donors and volunteers since it receives no government support.

The following are some of the ways you can support your society:

Membership—\$25 annual fee

Monthly, Quarterly or Annual Donation

United Way—Remember PSBC when giving through United Way

Special Events—Your participation in our special events makes a difference

Planned Giving and Bequests—Consider PSBC as a beneficiary in your Will

Support Groups

100 Mile House, Abbotsford, Burnaby, Campbell River, Carepartner Online, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, Cranbrook, Duncan/Cowichan Valley, Kamloops, Kelowna, Kelowna Caregivers, Kootenay Lake East Shore, Langley, Langley YOPD, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Nanaimo, Nanaimo Caregivers, Nelson, New Diagnosis 1 & 2 (Vancouver), New Westminster, North Shore Caregivers, Osoyoos/Oliver, Parksville/Qualicum, Parksville/Qualicum Caregivers, Penticton, Port Alberni, Powell River, Prince George, Quadra Island, Quesnel, Richmond, Richmond Carepartner, Shuswap/Salmon Arm, Sunshine Coast (Sechelt), Terrace, Trail/Castlegar, Tri Cities, Tri Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Caregivers, Vancouver Downtown Working Professionals, Vancouver West Side, Vernon, White Rock, White Rock Caregivers, YOPD Online

Editorial Statement

The views and opinions expressed within the pages of *Viewpoints* are not necessarily those of Parkinson Society British Columbia. The intention is to provide the reader with a wide range of material. Parkinson Society British Columbia welcomes submissions for the newsletter. The editor reserves the right to edit material and to withhold material from publication.

Articles contained in *Viewpoints* are for information only. PSBC 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.

Development of a method to determine the relationship between Parkinson's disease and the GCase enzyme

Glucocerebrosidase (GCase) is an important enzyme responsible for removing sugar residues from glycolipids. Patients with Parkinson's disease (PD) exhibit decreased activity of GCase in the brain and in blood cells. Recent research has suggested that mutation of the GCase gene is the greatest genetic risk factor for developing PD. These findings have triggered intense research efforts and the GCase enzyme is now recognized as a very promising clinical target to assist with early diagnosis of PD, as well as assessing disease progression. Until now, because it is so difficult to isolate, there was no efficient way to monitor and quantify the activity of GCase within clinical samples.

Dr. Christina Gros has developed a chemical probe that is better able to quantify GCase activity. Dr. Gros explains, "with just a blood sample from a patient, we can select cells and use our chemical probe to measure GCase activity. Our goal is to see if we can use these measurements of GCase activity to enable earlier detection of Parkinson's disease, before we can even see any behavioural symptoms."

With the development of this new technique, Dr. Christina Gros hopes to implement a new diagnostic tool for PD patients. This method of testing will be used in clinical studies to further characterize the relationship between PD progression and GCase activity. In the future, it may also be used to evaluate therapeutic approaches in a quantitative and non-invasive manner.



RESEARCH GRANT



PILOT PROJECT GRANT
\$55,333 over 18 months equally funded by Michael Smith Foundation for Health Research and Parkinson Society British Columbia. Each organization contributed approximately \$27,666 to this project.

RESEARCH PROFILE
Dr. Christina Gros,
Post-Doctoral Fellow

INSTITUTE
Simon Fraser University

In addition to the project described here, Parkinson Society British Columbia (PSBC) co-funds the following research projects with the Michael Smith Foundation for Health Research:

- *Roger Ashmus*: Development of Improved Substrates for Live Cell Imaging to Aid in Discovering New Glucocerebrosidase Therapeutic Agents
- *Kota Mizumoto*: Genetic Dissection of Neuronal Pattern Formation

PSBC funds the following research projects through the Parkinson Canada Research program:

- *Dr. Anish Kanungo*: Determining the impact of a multi-disciplinary movement disorder clinic on health outcomes and health care spending in Parkinson's disease
- *Dr. Michele Matarazzo*: Topographical analysis of the trajectory of dopaminergic degeneration in symptomatic and pre-manifest Parkinson's
- *Dr. Antonio Strafella*: Imaging synaptic pruning in Parkinsonisms
- *Frédéric Calon*: Clinicopathological investigations of the substantia nigra in Parkinson's disease
- *Jordan Follett*: Retromer-dependent regulation of RNA trafficking in Parkinson's disease

PSBC will announce its 2018 research contributions and commitments later this year. For the most up-to-date information, visit www.parkinson.bc.ca/research.

Dr. Wile Discusses Pain and Parkinson's disease



Dr. Daryl Wile, MD, MSc, FRCPC, completed a Bachelor of Science in Psychology at UBC, a Master of Science in Behavioral Neuroscience at McGill University and Doctor of Medicine followed by residency training in Neurology at the University of Calgary. He also holds a certification in Neurology from the Royal College of Physicians and Surgeons of Canada.

Dr. Wile completed a Clinical Movement Disorders Fellowship supported by Parkinson Canada at the Pacific Parkinson's Research Centre in Vancouver with a focus on genetic and brain imaging markers of clinical differences in Parkinson's disease (PD). He currently practices at the Okanagan Movement Disorders Clinic in Kelowna.



How common is pain in Parkinson's disease and what causes it?

Roughly 60–70% of patients with PD experience moderate to severe levels of chronic pain. While scientists are still working to determine the precise cause, we know that the neurological pain system can be broken, or have its function altered, due to Parkinson's. PD can also lead to shifts in pain tolerance, changes to the pain system in the frontal lobe of the brain and/or dopamine deficiency, which can be painful.

As doctors, we often hear that people diagnosed with PD have experienced muscle stiffness or pain for years. Some automatic movements are reduced in Parkinson's, like the swinging of arms while walking, which can cause stiffness. If this continues for long enough, it may result in frozen shoulder or inflamed muscle coverings.

Some people may feel superficial pain, such as the feeling of something crawling on their body, or a persistent tingling sensation. Other individuals may experience restless leg syndrome, another symptom of PD that will typically respond to dopamine treatment. These superficial symptoms can be uncomfortable or painful.

Often, in addition to PD related pain, people experience pain due to the wearing down of the muscles and joints related to general aging. Parkinson's patients may experience degenerative arthritis, joint pain and lower back pain that are, for the most part, unrelated to the disease. Pain before the onset of the disease appears in 25% of people. Painful rigidity, like dystonia, is also common, as is constant aching pain in a limb, such as frozen shoulder. Often, but not always, these PD related pain symptoms will improve with levodopa treatment.



What is dystonia?

Dystonia is a very common condition. A long time ago, it was considered a psychiatric condition, but over time we have learned that there are a number of genetic diseases that cause it. The word itself roughly means 'bad movement' or 'bad tone'. Dystonia is a sustained, abnormal posture of muscles that often

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leads to a twisting, cramp-like pain. Typically, when one group of muscles work to move a joint, the other muscle group is supposed to relax. When both muscle groups are active at the same time, as is the case in dystonia, it leads to twisting of the joints.

Doctors typically see dystonia as an “off” phenomenon. Suppose you have had PD for 15 years, and when you take your medications, they work for four hours. Then, when they wear off, you start feeling a twist in your limb. This is what we consider “wearing off dystonia”. You may notice that if you take another dose of your medication, the discomfort is relieved. I have a lot of patients who experience this. Alternatively, some people may experience peak dose dystonia as well or instead.

How is dystonia treated?

First, we look to see if the dystonia responds to dopamine treatment through levodopa or dopamine agonists. If that doesn't work, we might inject the muscle with botulinum toxin (Botox), or poisons that weaken the muscle for months at a time. The latter may sound strange, but it works for most patients.

What is dyskinesia?

Dyskinesia occurs when you have unwanted, writhing muscular movement. While dyskinesia is another condition that is not assumed to be painful, it can cause discomfort by moving an already painful limb.

What are other effects of pain?

Pain is associated with higher rates of depression and lower quality of life. When pain sensations reach the brain, they go to a part called the thalamus. When that stimulus is reached, it can override anything else that might be going on around you. This is why some people might say, “my hip is really

sore but I only notice it when I go to bed at night,” which is when external stimuli are removed.

How can you manage pain?

By utilizing a variety of pain management tools, you increase your capacity to prevent suffering. No drug will erase all the pain. This is a very tricky problem. You need to identify the individual components of what is causing you pain. What can you fix? What can you work around? How can support be increased to reduce your suffering?



Clinically, your doctor will likely seek to optimize dopamine treatment. Pain medications can also help. I often encourage patients not to try to suffer through pain. You should use pain medication as long as it is deemed safe by your doctor. Doctors typically try to avoid prescribing opiates when we can, since they can lead to confusion and constipation.

If you are experiencing severe PD related depression, you should pursue treatment, whether that comes through counselling, medication or a combination of the two. Depression can act as a multiplier of suffering. Addressing an underlying mood disorder can give you more capacity to deal with the pain you experience daily.

Some action steps you can take to manage pain are:

- Staying active by incorporating exercise that appeals to you.
- Practicing strong posture and stretching.
- Keeping track of when and where you have pain, relative to medication timing and other symptoms. This can help us identify and treat the pain.
- Discussing treatment options with your doctor.

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Vision and Parkinson's

Approximately 75% of people with Parkinson's disease (PD) experience vision challenges, including issues with the eyeball or eyelids, eye movements, wearing of the retina, facial recognition and spatial navigation and/or hallucinations. When exploring treatment options, it is important to differentiate between symptoms that might be PD related and the standard effects of aging. Some symptoms, especially hallucinations, might be impacted by levodopa and dopamine agents.

The Eyeball and Eyelid

Parkinson's can impact blinking as well as the development of mucus tears – both of which are required to keep the eyeball moisturized and comfortable. Because of this, people with Parkinson's (PwP) might develop dry eyes. To treat dry eyes, consider the following:

- 👁 Use artificial tears as frequently as needed. Gel-like artificial tears are better than watery artificial tears, since they are more similar to mucus tears.
- 👁 Slow the drainage of tears from your eyes using either a silicon punctal plug or lacrimal gel inserts. These are small devices that can be inserted into the tear duct to prevent rapid drainage of tears and mucus from the eye.



PwP may also experience blepharitis, or inflamed eyelids. This is a side effect of decreased blinking that can be caused by an excess of sebum, which is an oil that the skin produces. Symptoms of blepharitis include red eyes, swollen lids, excessive, watery tearing and light sensitivity. To treat it, you can place a warm compress on the eyelids for 5–10 minutes a day, up to four times a day. Wiping the lids with baby shampoo and water can also help. For acute flare ups or bad cases, a doctor may be able to prescribe antibiotics or topical steroids.

Eye Movements

PD can also impact the parts of the brain that control eye movement. This can lead to:

- 👁 **Convergence insufficiency:** this is the scientific term used to describe what happens when people have trouble moving their eyes inwards. This is the most common cause of double vision. While someone's distance vision won't be affected, close views (like reading) can lead to double vision. Convergence insufficiency can also cause blurred vision and discomfort. To treat it, you can wear an eye patch while reading, or, in consultation with an ophthalmologist or neuro-ophthalmologist, use prisms in your eyeglasses. Children who experience convergence insufficiency can sometimes correct the issue through exercises, however this method of dealing with the problem is less effective in older adults.
- 👁 **Square wave jerks:** this is a term for small, rapid eye movements to the left or right, which then return to the object in view. These jerking movements can be barely noticeable, but the more frequently you experience them, the more difficult it becomes to read. Unfortunately, there isn't a way to treat it. Deep Brain Stimulation (DBS) can help, but not everyone is eligible for the surgery. In the meantime, if reading is impacted, opting for larger text and visuals should help.



👁️ **Vertical gaze palsy:** This is difficulty in looking up and down. It can impact reading, going down stairs and eating meals. These activities can be especially challenging if the PwP is also experiencing a stiff neck.

👁️ **Ocular dyskinesia:** An estimated 10–15% of the PwP who experience dyskinesia, or uncontrolled muscular movements of the limbs, will experience dyskinesia of the eye. This might be managed through medication dosage adjustment in consultation with a physician.

The Mind-Gaze Connection

Some PwP report problems with identifying faces, facial expressions and spatial dimensions. If problems with the retina and eyeball are ruled out, it is possible that these challenges are due to PD related cognitive changes. It is also estimated that 25% of patients with PD experience complex visual hallucinations. This may be a side effect of levodopa, dopamine agonists, or due to Lewy body dementia. In all cases, it is important to discuss any changes in vision with a physician.

The Specialist's Role

Any adjustments to medications, as well as concerns with hallucinations or cognition, should be discussed with your family doctor, neurologist



or movement disorder specialist. If you are experiencing vision issues in PD, you may want to talk to your doctor about obtaining a referral to a neuro-ophthalmologist. Neuro-ophthalmologists come from either a neurological or ophthalmology background (specialty in the anatomy, physiology and diseases of the eyeball and orbit) and are experts in the connection between the brain and the eye. They often have experience dealing with Parkinson's patients and can accurately identify issues related to vision, eye movements and the eyeball.

This article is based on a recent *Ask an Expert* presentation by Jason Barton, neuro-ophthalmologist and Professor of Medicine (Neurology). The recording is available on Vimeo at: <http://bit.ly/Vision-PD>.

For more resources, including resources with additional information on medication and vision, visit www.parkinson.bc.ca. To speak with a staff member, you may email Caroline Wiggins at cwiggins@parkinson.bc.ca or 1-800-668-3330.

Do you have
Parkinson's
related legal
issues?

Blakes

Through a partnership with PSBC, the law firm of **Blake, Cassels & Graydon LLP** offers free of charge legal services to people with Parkinson's in British Columbia.

The Litigation Support Program from Blakes addresses legal issues such as discrimination against individuals with Parkinson's in the workplace; discrimination in accommodations, services or facilities that are generally available to the public; and, wrongful denial of disability insurance or denial of government services.

If you have a legal problem relating to Parkinson's disease, please contact **Jean Blake, CEO** at jblake@parkinson.bc.ca for more information.

Parkinson SuperWalk

Why We Walk

Parkinson SuperWalk is right around the corner; will you step up for the Parkinson's community?

Parkinson SuperWalk is the single most important awareness and fundraising event in British Columbia and across Canada. Beginning the weekend of September 8th & 9th, over 20 communities in BC will host walks to raise funds for local, life-changing Parkinson's programs.

Since PSBC receives no government funding, Parkinson SuperWalk plays a key role in providing the resources we need to offer:

- Educational opportunities such as our Communication and Swallow Workshops, Regional Conferences, Community Talks and Webinars.
- Free, short-term counselling to people with Parkinson's, caregivers and families.
- Training for allied healthcare professionals so that they may better support people with Parkinson's throughout their PD journey.
- New and improved informational resources, such as booklets and brochures.
- Continuing commitments to promising research.
- Ongoing advocacy for improved care.



THIS IS WHAT WALKERS ACROSS BRITISH COLUMBIA HAVE TO SAY ABOUT SUPERWALK...

I needed to connect. When I was diagnosed [with Parkinson's], I went into hiding; but I realized that I needed to talk to people and family, in addition to exercising.

—JUDITH N., VERNON

I have Parkinson's and I'd like to see something done about it rather than sitting down and accepting it.

—MERL S., ELK VALLEY/SPARWOOD

I walk and fundraise in memory of my grandfather. I'm just hopeful that there will be advancements in technology that will help people [with Parkinson's] regain their independence.

—MALINDAR S., VANCOUVER



PARKINSON SUPERWALK®

100 Mile House

Centennial Park
Cedar Avenue Entrance
Saturday, September 8

Burnaby

Confederation Park Track
Sunday, September 9

Chilliwack

The Landing Sports Centre
Saturday, September 8

Comox Valley

Courtenay Airpark Playground
Saturday, September 8

Cranbrook – Virtual Walk

Participants walk at a location, date and time that works for them.

Duncan

Cowichan Sportsplex
Saturday, September 8

Elk Valley

Senior Drop In Centre
Saturday, September 8

Fort St. James

Nak'azdli Health Centre
Saturday, September 15

Gingolx

TBA
Sunday, September 9

Kamloops

Riverside Park/Rotary
Bandshell
Saturday, September 8

Kelowna

Waterfront Park /Concession Plaza
Saturday, September 8

Nanaimo

Westwood Lake Park
Saturday, September 8

Oliver

Oliver Community Centre
Sunday, September 9

Parksville

Parksville Community Park
Saturday, September 8

Pitt Meadows/Maple Ridge

Spirit Square, Pitt Meadows
Saturday, September 8

Powell River

Timberlane Park – Track
Sunday, September 9

Prince George

Lheidli T'enneh Memorial Park/By Band Shelter
Saturday, September 8

Richmond

Minoru Park/Running Track
Saturday, September 8

Salmo

Salmo Valley Youth and Community Centre
Saturday, September 8

Salmon Arm

McGuire Lake Park
Saturday, September 15

Surrey

Bear Creek Park/Bear Creek Pavilion
Sunday, September 9

Terrace

Grand Trunk Pathway
Millenium Trail
Saturday, September 15

Vancouver

Stanley Park/Ceperley Playground
Sunday, September 9

Vernon

Polson Park
Saturday, September 8

Victoria

Esquimalt Gorge Park
Saturday, September 8

White Rock

Kintec Store Parking Lot
Sunday, September 9

Walk dates and times may be subject to change.

Parkinson SuperWalk in British Columbia is operated by Parkinson Society British Columbia under license from Parkinson Canada.

Register or donate today! Visit www.parkinson.bc.ca/superwalk

My stepfather was passionate about finding a cure for Parkinson's disease, and did his best to participate in local research studies while learning everything he could about living with PD. I continue to walk in [his memory], and his passion for eventually finding a cure.

—JASON M., VICTORIA

Parkinson SuperWalk is an event where people come together in celebration of the Parkinson's community. By focusing on the sense of community and being proactive about raising funds, it helps us deal with our diagnoses in a positive way.

—AUDREY C., MAPLE RIDGE/
PITT MEADOWS

Now, [my favourite part of SuperWalk], is the joy in my kids' faces during the event. They like the clown and balloon animals the best.

—BRIANNA S., KAMLOOPS



Photo taken by Team Rock Steady
Boxing New Westminster

Parkinson's and Creativity

Creative expression varies from person-to-person. For some, it means generating out-of-the-box ideas. To others, it takes the form of self-expression through painting, singing, music or dance. Creativity's role in Parkinson's disease (PD) has recently been explored through clinical research as well as practical applications, such as art therapy. So, how does PD impact creativity and how can creativity, in turn, be used as a tool to help manage the disease?

The Neuroscience of Creativity

Recently, scientists have been challenging the notion that creativity takes place in the “right brain”. Instead, various networks of the brain have been found to activate at different stages in the creative process (Kaufman, 2013). To build these brain networks, neurotransmitters like dopamine send brain signals from one nerve cell to another. In Parkinson's disease, the cells which produce dopamine in the substantia nigra portion of the brain degenerate over time. Clinical symptoms of PD occur when more than half of the dopamine-producing cells are lost. The lack of dopamine affects motor symptoms such as walking and writing, and can cause involuntary movements. Mood and thought are also impacted.

New insights suggest that dopamine may also play a role in creativity. In an interview with the Israeli Ministry of Foreign Affairs, Dr. Rivka Inzelberg, former senior neurologist at Tel Aviv University's Joseph Sagol Neuroscience Center, points out that Vincent Van Gogh's psychotic episodes, during which high levels of dopamine are released in the brain, often resulted in some of his best work. She conducted a research study where Parkinson's patients and a control group (consisting of people without PD) were asked to interpret pictures, answer imagination-provoking questions and explain metaphors. Her team found that people with Parkinson's (PwP) appeared to better understand the abstract images and provided more metaphorical,

symbolic interpretations of the questions asked of them. Interestingly, PwP who were taking larger doses of dopamine producing agents provided more creative answers than PwP who were on less medication (Chang, 2015). So, while dopamine deficiency in Parkinson's disease may impact creativity, medications like dopamine agonists and levodopa may also lead to periods of creative inspiration.

Creativity as Therapy

Liliana Carreras is a British Columbian with Parkinson's who started painting years before she knew she had the disease. At the time, she experienced depression, and reluctantly joined a friend at an art workshop. Liliana explains, “once I spent a few minutes with a group of artists of all ages and abilities, I realized this was for me. I fully immersed myself and poured my soul onto a canvas and absolutely fell in love with the process, the atmosphere, the sense of accomplishment and the sudden spike in energy I felt. It became the best therapy for me and I couldn't wait for the next session. I started working on my own at home and painting became my passion during every free moment I had. I quickly learned it did not matter if others liked what I did. As long as I was pleased with the process, I would continue to create. I felt encouraged, hopeful, empowered, in love with life and all that it offered.”

Years later, art continues to be a healing force for Liliana, allowing her to explore her personal identity and creativity. She has opened an online store through Etsy and started selling her work, which has allowed her to connect with people from all over the world. Liliana says that “others have also noticed my fine motor skills are great, as I hardly tremble when my mind is concentrating on the task at hand... Art has helped me in many ways deal with aspects of an otherwise gloomy outlook of this chronic illness.”

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Pictured: Liliana at a Painting for Parkinson's workshop presented by Robyn Murrell and Heidi Clarkson. This afternoon event will return August 22, 2018.

Paddi McGrath is a Vancouver-based art facilitator who has facilitated art sessions for numerous people with advanced Parkinson's. In an email interview, she states, "anxiety and confusion is a big part of the disease and art can be magical in its ability to produce calm. I think this is one of its greatest benefits. One of our residents with advanced Parkinson's has the reputation of creating havoc in his living area because he can't stop moving due to anxiety. He crashes into furniture and walls in his wheelchair and constantly calls out for help. As soon as he starts painting in our studio, he calms down and can focus for a couple of hours."

People with Parkinson's across the province have found creative ways to help manage the many symptoms of the disease. Regardless of whether the creative outlet is visual art sessions, song groups like SongShine or dance programs like Dance for PD, it is important for people to stay physically and mentally active while socializing. Most people find that these activities are enjoyable, relaxing and, when conducted in a social setting, can help alleviate feelings of isolation and depression.

For the most up-to-date information on recreational activities that can be beneficial for PwP, please contact Caroline Wiggins at cwiggins@parkinson.bc.ca or 1-800-668-3330.



CREATIVITY as Awareness Building

In an effort to continue to raise awareness of Parkinson's disease throughout the year, Parkinson Society BC has rented "the Moat" gallery space at the Vancouver Public Library's West Georgia branch from August 1st to August 31st, 2018. During this period, art created by residents of BC who live with Parkinson's disease, or family/carepartners of those living with the condition, will be displayed. The exhibit will be accessible to the public from 6:00 am – 10:00 pm Monday through Saturday and from 8:00 am – 7:00 pm on Sundays. Some last minute submissions may be accepted on a case by case basis.

To learn more about the exhibit, please visit www.parkinson.bc.ca/art-exhibit or contact Jovana Vranic at 1-800-668-3330 or jvranic@parkinson.bc.ca.

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Chang, G. (2015, August 20). *The dopamine effect? Why people with Parkinson's are more creative*. Retrieved from <http://parkinsonslife.eu/the-dopamine-effect-why-people-with-parkinsons-are-more-creative/>

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Respite for Caregivers



As a caregiver, it is easy to lose sight of your own needs and forget to prioritize your own self-care; however, it is important to be realistic about what you are able to achieve by setting personal boundaries and sticking to them. Sometimes, this will mean saying no to demands that are unreasonable, unmanageable or inappropriate.

Respite Services

Respite services provide caregivers with a period of short-term relief from care duties. They may also help you with caregiving duties in the home, so your loved one can continue to live in your household for longer.

Some respite services are publicly funded. To access them, you will need to contact your local health authority to request an assessment for home and community care services. The health authority will need to know whether you are looking for in-home or institution services, as well as the address of the person with Parkinson's. The next step is an assessment from the authority's intake department, which should be able to set you up with a case manager. Alternately, a healthcare professional, like your physician, can make a referral to a case manager on your behalf. If a person with Parkinson's is in the hospital, assessments are done there.

In-Home Support

British Columbia has identified a number of services that are administered by the five healthcare authorities and categorized as Continuing Care. These include:

- Home support services (such as medication management)
- Adult day services
- Meal programs, like Meals on Wheels
- Short stay assessment and treatment centres
- Home oxygen programs
- Assisted living services
- Home care nursing

Adult Day Services or Programs

Adult day programs are community-based, day-long or half-day social and recreational programs offered for groups of people who need care. These programs focus on supporting exercise, toileting, eating and mobility issues. There is usually a small fee affiliated with the services, but the fee can be waived if financial need is demonstrated.

Short-term Residential Care

Sometimes, due to an injury or acute health challenges, short-term residential care (for less than 3 months) might be necessary. According to the BC Government, short-term residential care costs about \$25 to \$45 a day. Like the Adult Day Programs, people with demonstrated financial need may qualify for a reduced rate.

Negotiating with Employers

Caregiving can be emotionally and physically draining. If you are having difficulty managing work and caregiving commitments, consider asking your employer

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about family-friendly organizational policies. Options like flexible work arrangements, family leave and Employee Assistance Programs, are becoming increasingly common (Department of Social Development, 2016). While this is not a formal kind of respite, being able to balance work obligations and caregiving tasks can make a world of difference.

Informal Relief & Support

Productivity consultant David Allen says, “You can do anything, but not everything” (Bergeson, 2016). This is why prioritizing caring with other obligations in your life is so important. There is no shame in taking advantage of health services available to you. Additionally, asking for help with caring or household chores from close family members or friends can be beneficial to all parties involved. Even services that charge a small fee, like cleaning services, can help with the load you are bearing.

This article has been adapted from an excerpt in *A Comprehensive Guide for Parkinson’s Caregivers*, a recent publication from PSBC. This publication is available online at bit.ly/psbccaregiversguide or in print (shipping fee may apply) from the PSBC office. To speak to a staff member about obtaining your copy, you may call toll-free 1-800-668-3330 or email info@parkinson.bc.ca.

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Department of Social Development – New Brunswick. (2016). *Caregivers’ Guide: Practical information for caregivers of older adults*. Retrieved from <http://www2.gnb.ca/content/dam/gnb/Departments/sd-ds/pdf/Seniors/CaregiversGuide.pdf>

DR. WILE DISCUSSES PAIN & PARKINSON’S DISEASE

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What are some complementary therapies that can help with pain?

Many studies have looked into complementary therapies. I think that with any of these treatments, you should prescribe yourself a goal, give yourself a time frame and assess whether it fixes the problem you want it to fix. Yoga, tai chi and stretching can all be helpful to improve range of motion, reduce muscle strain and avoid painful joint contractures. Exercise can also help with mood and motivation, brain blood flow, neuroplasticity and muscle strength. Stretching is also very important for muscular strength and pain management.

This *Ask an Expert* feature was adapted from Dr. Wile’s presentation at *Moving Forward, Together*, a



Provincial Conference hosted by Parkinson Society British Columbia in 2017. Recordings from this event are still available at www.parkinson.bc.ca/movingforward.

Champions for Parkinson's

Christmas Light Display in Surrey

A private residence in Surrey lit up with a beautiful Christmas light display during the 2017 holiday season and, with the support of the Surrey Firefighters' Charitable Society, raised over \$600 for PSBC!

Phillips Brewing & Malting Company

In February 2018, Phillips Brewing & Malting Company designated Parkinson Society BC as their charity of the month. Thanks to the generosity of the company and craft beer lovers, a total of \$1,160 has been donated to PSBC's programs and services. This is the second year in a row Phillips has supported PSBC.

Sweetheart Pizzas

On February 14th, 2018, Me-n-Ed's Pizza Parlors offered diners their special heart-shaped Sweetheart Pizzas. For every pizza sold, \$1 was donated to PSBC for a total of \$305. That's amore!

Pies for Parkinson's

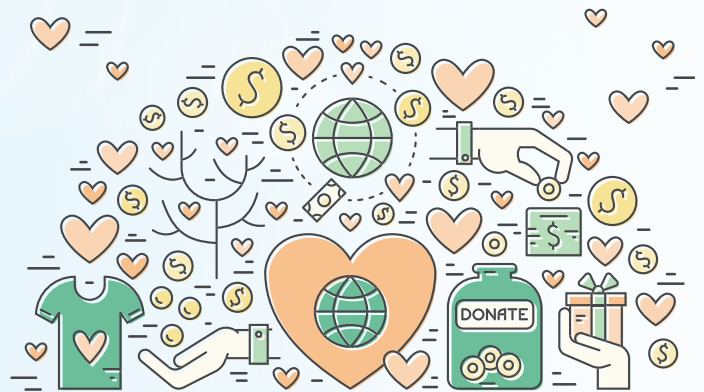
Casa Loma Retirement Home residents in Courtenay hosted their annual Pie's for Parkinson's event in March 2018. Residents raised \$160!

5th Annual Chocolate & Beer Tasting

Organized by Sherri and Julian Zelazny, this event took place for a fifth year on March 25th, 2018. Hosted at Postmark Brewing, guests enjoyed an evening of delicious handmade chocolates from Take a Fancy and beer from Postmark. The evening raised \$2,377 for Parkinson's!

Spin for Parkinson's

On April 11th, 2018, which also happens to be World Parkinson's Day, Heather Lind at Wholey Fit! hosted a spin class by donation in her fitness studio. Participants got a fantastic workout for a good cause, and raised over \$280!



PSBC's Spring Online Auction

This year's annual Spring Online Auction featured a variety of exciting items, including weekend getaways, golf experiences and sporting tickets. Bidders raised over \$2,240!

Spring Bouquet Sales

Evie & Olive Floral Design sold tulip bouquets between March 21st and April 15th, 2018. From every bouquet sold, \$20 was donated to PSBC, and the initiative raised over \$200!

Special Thanks

Burnaby Lions Club

PSBC thanks the Burnaby Lougheed Lions Club for their generous gift of \$500. They are a strong, diverse group of men and women who work hard to support their local community.

Fraternal Order of Eagles Vancouver Aerie No. 2075

Our deepest gratitude to the group for their generous gift of \$1,500.

Interested in becoming a Champion for Parkinson's and helping raise critical funds for programs, services, advocacy efforts and research contributions? [▶](#) Contact Mirela Prime at mprime@parkinson.bc.ca or 1-800-668-3330.

Active Living Webinar Series

Parkinson Society BC is hosting a new, Active Living Webinar Series with presentations taking place every Tuesday this August. You'll learn from a variety of healthcare professionals as to how they can support people with Parkinson's live healthier and more active lives.

Date: Every Tuesday in August

Time: 10:00 am – 11:00 am

Location: Via webinar

Community Talk: Emotional and Mental Health, Prince George

Join PSBC for an afternoon of education at the Spruce Capital Senior's Recreation Centre. Clinical Counsellor, Myriame Lépine Lyons, will discuss emotional and mental health for those affected by Parkinson's disease. This talk is for both people with Parkinson's and their carepartners/caregivers. A light lunch will be provided and the education session will begin at 1:00pm.

Date: Saturday, September 29, 2018

Time: 12:00 pm – 3:30 pm

Location: Spruce Capital Senior's Recreation Centre, 3701 Rainbow Drive
Prince George

Cost: Member \$10
Non-member \$15

Time Out for Carepartners, Kelowna

Join us for a day of education, socialization and relaxation. Expert speakers will share experiences and strategies for coping with the complexities that arise as a result of Parkinson's disease (PD). Lunch and light refreshments will be provided.

Date: Saturday, October 20, 2018

Time: 10:00 am – 2:30 pm

Location: Ramada Kelowna Hotel & Conference Centre, 2170 Harvey Avenue, Kelowna

Cost: Member \$30
Members (couple/pair) \$45
Non-member \$40
Non-members (couple/pair) \$55

Regional Conference, Vancouver

Date: Saturday, November 24, 2018

Time: 1:00 pm – 4:15 pm

Location: Alice MacKay Room, Library Square Conference Centre, 350 West Georgia Street, Vancouver

Cost: Member \$15
Members (couple/pair) \$25
Non-member \$25
Non-members (couple/pair) \$45




For registration and more information, please visit: <http://www.parkinson.bc.ca/education-events> or call PSBC at 1-800-668-3330

World Parkinson Congress in Kyoto, Japan**SAVE
THE
DATE**

The 5th World Parkinson Congress will be held in Kyoto, Japan from June 4–7, 2019. The goal of the event is to unite the global

Parkinson community for a high-level, scientific and educational program. Organized into four days of plenary sessions, workshops and discussions, WPC 2019 will explore cutting edge science and clinical research as well as advances in treatments designed to improve care and quality of life for people living with Parkinson's disease.

This event is presented by the World Parkinson Coalition®. More information is available at www.worldpdcoalition.org.

Individuals or groups who are interested in attending are encouraged to arrange their own transportation. Support staff have been busy exploring travel options available.  If you have questions about arranging transport, please contact Myriame Lépine Lyons at mlepinelyons@parkinson.bc.ca or 1-800-668-3330.

ABOVE AND BEYOND AWARDS

ABOVE AND BEYOND AWARDS

ON MAY 5TH, 2018, at Parkinson Society British Columbia's Annual General Meeting, we recognized people with Parkinson's and their caregivers/carepartners who were nominated by their peers for going above and beyond in their communities. These volunteers dedicate themselves to celebrating every day with joy, compassion and understanding.

Special recognition was extended to the following individuals:



Bob Thompson has a warm, inclusive nature, and for many years has brought positivity and energy to the Kelowna Partners in Parkinson's support group. He also serves on PSBC's Board of Directors.



Marie Jurick is an active member of the Nanaimo Support Group and local exercise programs.



Jolyon Hallows cared for his wife Sandra, who lived with Parkinson's disease for over 20 years. He continues to share his experiences to strengthen and support the caregiving community.



Sherri Zelazny serves on PSBC's Board of Directors. As a Registered Speech-Language Pathologist, she was instrumental in developing PSBC's Communication & Swallow Workshops, which she continues to deliver.

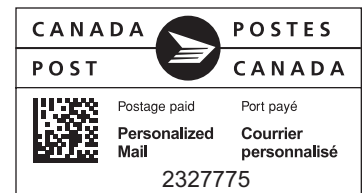
Our deepest gratitude to all other nominees:

- Barbara Peterson
- Edith Elliott
- Jillian Carson
- Pat & George Mauch
- Chris Olsen
- Gail Guise
- Joanne Long
- Valerie Swannell
- David & Betty Giesbrecht
- Gail Soliski
- Kate Wood
- Wayne Van Steinberg
- Diane Daignault
- Harold Olsen
- Mark Bullock
- Mary de Souza
- Doug Pickard
- Ileene Davis

▶ If you have questions about volunteering with PSBC, please contact:
Mirela Prime, Resource Development & Volunteer Coordinator
mprime@parkinson.bc.ca | 604-662-3240 | 1-800-668-3330



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