

Viewpoints

Parkinson
Society
British
Columbia



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

**SUMMER
2015**

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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 the many ways you can support your society:

Membership—\$25 annual fee

Monthly or Quarterly 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

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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.

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100 Mile House, Abbotsford, Burnaby, Campbell River, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, Courtenay/Comox Caregivers, Cowichan, Cranbrook, Creston, Elk Valley (formerly Sparwood), Fort St. John, Kamloops, Kelowna, Kelowna Caregivers, Ladner, Langley, Lions Bay, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Mission, Nanaimo, Nelson, New Diagnosis 1 & 2 (Vancouver), New Westminster, North Shore, North Shore Caregivers, Osoyoos/Oliver, Parksville/Qualicum, Parksville Caregivers, Penticton, Penticton Caregivers, Powell River, Prince George, Quadra Island, Richmond, Shuswap/Salmon Arm, Shuswap/Salmon Arm Caregivers, South Sunshine Coast (Sechelt), Surrey, Terrace, Trail/Castlegar, Tri-Cities, Tri-Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Caregivers, Vancouver West Side, Vernon, White Rock

DR. MARTIN MCKEOWN

answers your questions on Medication for Parkinson's disease



Dr. Martin McKeown is a clinical neurologist with an interest in Movement Disorders, particularly Parkinson's disease. He is currently the Pacific Parkinson's Research Institute's (PPRI) Chair of Parkinson's Research and

Clinical Director of the Pacific Parkinson's Research Centre. The unique combination of his medical training and engineering background is reflected in his research where engineering principles are applied in investigating disease mechanisms and potential treatments.

What types of medications are used for treating Parkinson's disease?

Since the main biochemical abnormality in Parkinson's is reduced dopamine, most medications attempt to normalize this deficit. Levodopa (L-dopa) medication, often combined with Carbidopa to prevent gut upset, will ultimately be used by almost all patients. It is converted in the brain to the naturally occurring brain chemical dopamine. Since this medication was introduced over 50 years ago, we are very familiar with its pros and cons. While not perfect, it is an excellent treatment and quite safe to use.

There are also medications that can prevent dopamine from being used up too quickly and synthetic forms of dopamine (dopamine agonists) that try to improve on some aspects of L-dopa—but they have their own unique side effects.

Generally, a variety of medications can be used to treat many of the issues that may occur in Parkinson's, including dyskinesias, memory difficulties, depression and low blood pressure when standing up.

Do these medications stop the progression of the disease?

The best way we know to slow the progression of the disease is exercise. However, it is currently unclear what type of exercise is best—likely the exercise must be vigorous enough to make you sweat. Since medications like L-dopa make it easier to exercise, they may indirectly contribute to slowing the disease. There was some preliminary evidence that rasagiline (“Azilect”) may slow the progression of the disease, although this is controversial.

Incidentally, years ago there was a theoretical concern that medications like L-dopa may actually speed up the disease while merely treating the symptoms. Fortunately, this has clearly been shown *not* to be the case. As mentioned earlier, we have such extensive experience with L-dopa that we can say with some authority it does not negatively affect disease progression. However, this notion is still held by many in the community and may contribute to “L-dopa phobia,” which may prevent people from taking medication.

What are the common side-effects of these medications?

Medications for PD are usually well-tolerated. The most common side effect being stomach upset, and this is usually best managed by slowly initiating therapy. After someone has been on L-dopa for years, they may experience dyskinesias, or involuntary movements, when they have too much medication. Based on animal studies, we believe that this can be prevented by taking smaller, but more frequent doses, as this reflects the more natural state of dopamine.

Dopamine agonists may have a range of side effects including decreased blood pressure, excessive sleepiness, swelling of ankles and cognitive changes.

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ASK AN EXPERT

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More recently, the dopamine agonists have been shown to make some people more impulsive. This can result in pathological gambling, hypersexuality, excessive shopping, etc. However, dopamine agonists often have a positive effect on mood.

Dosing, more frequently, is a bit less convenient; however, I believe we are seeing fewer and less severe dyskinesias than in the past. Often people confuse effects of the disease with side effects of the medication. For example, constipation is a characteristic of Parkinson's and not normally a side effect of the medication, but sometimes people will attribute their constipation to a medication side effect.



? Will the medication treat all my symptoms?

The effects medications have tend to vary by the individual. In the early stages of the disease, medications like L-dopa can almost normalize function, but tremors can be difficult to treat. However, people with tremors can take comfort in the fact that it is often associated with a milder form of the disease.

As people live with the disease longer, they may find that newer symptoms may not be improved with medication. For example, loss of balance does not typically improve with medication. Finding the right dosage and combination of your medications for your specific situation is vital. Working with your neurolo-

gist and your healthcare team is essential to finding the best medications and routine for your treatment.

? Are there medications to treat the non-motor symptoms of Parkinson's?

There are many medications that can be used to treat some of the non-motor symptoms such as excessive sleepiness, bladder difficulties, restless legs syndrome, sleeping difficulties, depression, anxiety, low blood pressure on standing up, dementia, constipation, sexual dysfunction, psychosis, painful dystonia, swallowing difficulties and drooling. Treatments for these symptoms are best discussed with your doctor and/or neurologist.

? Are there any natural treatments for Parkinson's disease?

- *Exercise* is probably the best natural treatment. You may find tai chi, dance or meditation to be helpful.
- *Melatonin* is often useful for sleep.
- *Mucuna Pruriens*, or *velvet bean*, contains L-dopa, but it has no carbidopa to assist with nausea. It is also harder to maintain a stable dosage, as the amount of L-dopa may vary from plant to plant—thus it is probably better to use the purified form available in the tablets.
- *Coenzyme Q10* is expensive, and a recent study had to be stopped prematurely because there was no significant effect.
- There is some suggestion that people with Parkinson's may be deficient in *vitamin D*, *vitamin B6* and *B12* and so replacing these is probably warranted.
- *Caffeine* may also help some aspects of Parkinson's.
- Recent studies have suggested that gut bacteria are altered in people with Parkinson's, indicating a potential role for *probiotic-type treatments* in the future.
- Many people report improvements in their symptoms after retiring, vacationing in *warm climates* and even travelling to places at *higher altitudes*.

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How should I take my medication? With or without food? Should I avoid protein in my diet?

We have found that people who take their medication consistently and on time tend to do better in the long term. The issue with food can be confusing. Because early on in the disease mild nausea can be a common complaint, and medication is absorbed past the stomach, we often suggest taking the medication with food. However, protein can interfere with the medicine getting into the brain. We therefore

suggest that people take the medication at least one hour before/after major meals, and with a light snack such as a cracker or a piece of fruit. You may also consider taking it with some ginger tea or sparkling water. For more information on this, please see the help sheet available through Parkinson Society British Columbia titled "Levodopa (Sinemet) and Protein: Medication Absorption Concerns."

What other treatments are effective for treating Parkinson's disease?

Deep Brain Stimulation (DBS) can be a very effective treatment for Parkinson's disease, but not all subjects are suitable for surgical treatment, and DBS is invasive. In some cases where dystonia results in painful cramping of the muscles, some relief can be obtained by injection of botulinum toxin. We are currently investigating novel treatments, such as neurobiofeedback, and non-invasive brain stimulation which may prove helpful.

Champions FOR PARKINSON'S

Parkinson Society British Columbia

Plan your own independent fundraising event!

Become a Champion for Parkinson's and plan your own independent community fundraising event!

Wedding season is just around the corner! Now that you've found your soulmate, why not share the love by accepting donations to Parkinson Society British Columbia in lieu of gifts? Donations will fund research, grow support networks and improve quality of life for those living with Parkinson's.

FOR MORE INFORMATION, PLEASE CONTACT:

Cecilia Tupper, Director, Resource Development | 604 662 3240 | 1 800 668 3330 | ctupper@parkinson.bc.ca



Measuring the brain's white matter and how it affects thinking in Parkinson's disease

One of the substances in the central nervous system that appears critical for healthy thinking and reasoning is myelin—the fatty tissue known as white matter in neurons, which connects and conducts the signals cells send to one another. The more myelin, the faster the connections among cells.

At the University of British Columbia, physicist Alex MacKay and his colleagues have created a new technique using Magnetic Resonance Imaging (MRI) to measure the myelin in people's brains. Now, they're testing the theory that the breakdown or loss of myelin within the brain contributes to the problems in thinking and reasoning that many people with Parkinson's disease experience, sometimes before the stiffness, rigidity and tremors that more commonly flag their diagnosis.

MacKay and his team have demonstrated that people with multiple sclerosis (MS) have less myelin and also have cognitive problems, and drug companies are already testing medications that can either reduce or prevent the breakdown of myelin. If MacKay can demonstrate that the same process occurs in people with Parkinson's, the new drugs under development for MS and other diseases could ultimately help people with Parkinson's disease too. The companies will also have a way to tell if their drugs are repairing myelin or stopping its loss.

"It's a very exciting time," says MacKay. "Clinical trials are happening as we speak."

MacKay will use this non-invasive imaging technique to measure the myelin in the brains of people with Parkinson's disease, particularly in the frontal lobe, which controls judgment, reasoning and other forms of executive functioning. The people participating in the imaging study will also undergo cognitive testing, so the researchers can correlate their thinking and reasoning skills to their myelin measurements.

■ Research Project

Assessment of "normal appearing" white matter in Parkinson's disease and its association with cognitive dysfunction.

■ Pilot Project Grant

\$45,000

■ Project Description

"Myelin (white matter) speeds things up by a factor of 100, but if you have a problem with myelin, this speeding-up doesn't happen. People don't think as well."



This is the first time researchers have used MRI scans to investigate a link between myelin and Parkinson's, and there is still a lot of work necessary to understand how myelin breakdown is related to the death of dopamine-producing cells, MacKay cautions. But he hopes this new line of enquiry will explain one portion of the Parkinson's puzzle—a puzzle in which he has a personal stake.

"I have two very good friends who have Parkinson's disease," says MacKay. "I relate very much to this disease and how rough it is on those who have it."



Biography

Dr. MacKay is a physicist who trained at Dalhousie, UBC and Oxford University. Dr. MacKay is a full professor at the University of British Columbia with a joint appointment in the Radiology and Physics & Astronomy departments. He directs the UBC MRI Research Centre and is co-Director of the Graduate Medical Physics Program at the University of British Columbia.

Two decades ago, his research group pioneered a magnetic resonance technique which makes images of the myelin component of white matter. Myelin water imaging has by now been applied to a wide variety of neurodegenerative diseases, including multiple sclerosis, schizophrenia and phenylketonurea. This Parkinson Society grant will support the first application of myelin water imaging to Parkinson's disease.



Advocating for further investment in the deep brain stimulation program

According to the Ministry of Health, there are now 12,500 British Columbians living with Parkinson's disease (PD). Due to the aging population, the number of Canadians over 40 living with PD is expected to rise 65% by 2031. Though the vast majority of people have success in treating symptoms through medications, there is a small percentage of people who may benefit from surgical procedures such as Deep Brain Stimulation (DBS).

In the early 1960s, the first surgical treatment of Parkinson's disease (PD) in British Columbia was performed. Later, after completing a fellowship in Europe, Dr. Ian Turnbull improved on this procedure by allowing more accurate target localization and therefore reducing inconsistent results (Honey & Palur, 2001). Today, DBS is the fastest growing surgery for Parkinson's, "an operation where an electrode is implanted in the brain and used to modulate the region of the brain causing unwanted symptoms" (Vancouver Coastal Health, 2012). The electrode is then connected to a stimulator subcutaneously that sits below the clavicle. The stimulator is not activated until several weeks post-surgery, once the swelling has subsided. Continual visits are scheduled to change stimulation parameters to optimize symptom relief and a replacement battery is required approximately every 3 to 5 years (Honey & Palur, 2001).

Currently, Dr. Christopher Honey is the only neurosurgeon in BC qualified to perform DBS surgeries. He has built the DBS program into an internationally recognized centre of excellence for patient care and research. While the Vancouver Coastal Health Authority and the Ministry of Health have recently agreed to continue to fund DBS surgery for those that qualify, the current static funding is insufficient to cover costs

of timely follow-up care in the DBS clinic and will not be enough to accommodate the documented growing prevalence of Parkinson's disease in B.C.

The wait time for DBS in BC involves two waiting lists. The first (W1) is the time from when your neurologist puts in a referral for surgery until the time of your preliminary neurosurgical appointment. W1 is up to two years for an initial visit with a movement disorder specialist. The second (W2) is the time from deciding you want surgery to the day of surgery. W2 is approximately one year. As Parkinson's disease is a progressive neurological disorder with a window of opportunity allowing some to improve the condition surgically, a lost year of benefit may be devastating for a patient. Furthermore, in the past, annual funding for the procedure has often been depleted by late November or early December. This has produced a difficult situation of postponing procedures until after April when the new fiscal year begins—again contributing to lengthening waitlists.

At Parkinson Society British Columbia, we are strong advocates for increased funding which may allow for more people to have this life changing surgery, as well as greater pre- and post-operative support. Five years ago, our generous donors made it possible to provide funding to Dr. Honey's DBS program for surgical equipment.

As a society we will continue to advocate for the interests of our community and members, but we are only as strong as the voices that back us. In the case of DBS, we know that members of the Parkinson's community can and have benefitted from this surgery. We urge you to join us in our advocacy efforts to encourage the Vancouver Coastal Health Authority and the Ministry of Health to invest in the expansion of the program and funding for Movement Disorder clinics across B.C.

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The following are the stories of two individuals who received Deep Brain Stimulation surgery, describing the impact that the procedure had on their lives. We hope that in reading them you are inspired to take action to better the lives of British Columbians living with Parkinson's disease.

■ **SUSAN ALLAN** was diagnosed with Parkinson's disease in 2007 at just 47 years old. At the time of her diagnosis, she was a financial planner, but as her condition progressed she was unable to perform her duties, resulting in the loss of her job. Finding that her medication was wearing off in less

than three hours and she was continually increasing dosage and frequency, she decided another approach needed to be taken. In the fall of 2014, she underwent Deep Brain Stimulation surgery as a last resort in her attempt to manage the disease.

About the surgery she says, "Everyone's experience with Parkinson's is unique as dopamine plays crucial roles in many of the body's tasks and functions. Before my surgery, I was often sleepless and up many times during the night, frozen and requiring much assistance to move. I now am up once per night and require minimal assistance."

Before her DBS surgery, Susan often found herself freezing on the spot in many places, including crosswalks and bathrooms. Now, she can move around much better and her friends have noticed a positive difference in her confidence level. Recently, she was able to travel across the Lower Mainland to visit her daughter. "This sort of travel is taken for granted by most people"

she says, "but has been a gift to me provided by the DBS surgery." As the procedure gave her back some independence, Susan is now an advocate for the expansion of funding for the surgery as it provides hope and improved quality of life for those living with Parkinson's.

■ **STEPHEN GARDNER** was diagnosed with Parkinson's in February of 2003 at the age of 43. Like many Parkinson's patients, after several years he became dependent on medications to manage his symptoms. While the medications helped, the dosage resulted in adverse side effects, which for Stephen involved dyskinesia and compulsive behaviours. He often found himself writhing and wriggling which he found embarrassing and it affected his work, family and social life.

He says, "I became a slave to medication. Upon waking, I would wait 30 to 45 minutes before my medications 'kicked in'. During this time I could barely walk due to the stiffness that comes with Parkinson's." Once the medications started to work, their effects would wear off after only a few hours, making it difficult to schedule life and work commitments. Fortunately for Stephen, he had an understanding employer who accommodated his condition as well as receiving considerable support from his family.

Being dependent on medication also meant being reliant on pharmaceutical companies. Once the patents for brand name medications expired (Controlled Release Sinemet), and generic versions became available, he noticed deterioration in his condition as the composition of medication changed. For several weeks he tried different versions of Sinemet, not knowing from one day to the next how his body would respond. Eventually, he resigned himself to the fact that he was at least getting some benefit from the medication.



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Like many patients, Stephen was subject to a long waiting list for DBS surgery. Though he was identified as a candidate in the fall of 2010, it wasn't until October 2012 that he was accepted as a patient and underwent the procedure in March 2013. By the time he was referred for DBS surgery, he says his dyskinesia was so bad that people would cross the street to avoid a potential incident with his flailing arms.

Following the surgery, Stephen was immediately able to reduce his medications. Now, he takes only 40% of the medications he took pre-DBS. He now experiences much less fluctuation between the on and off state, and no longer has to schedule his life around medications. Stephen adds, "My dexterity has improved and the dyskinesia is almost unnoticeable. Many friends and colleagues that were unaware of my condition are surprised to learn I have Parkinson's disease."

For more information on how to get involved in Parkinson Society British Columbia's advocacy initiatives, please contact:

**Jean Blake, Chief Executive Officer
Parkinson Society British Columbia
604 662 3240 | 1 880 668 3330
jblake@parkinson.bc.ca**

References:

Honey, C.R., & Palur, R.S. (2001). Surgery for Parkinson's disease. *BC Medical Journal*, 43(4), pp. 210-213. Retrieved from: <http://www.bcmj.org/article/surgery-parkinsons-disease>

Vancouver Coastal Health. (2012). *Deep Brain Stimulation (DBS)* [Brochure]. Vancouver: Vancouver Coastal Health.



West Coast College of Massage Therapy

613 Columbia Street
New Westminster, BC

(Near 6th Street, one block from Columbia Skytrain Station)



West Coast College of Massage Therapy holds a special massage clinic for people with Parkinson's, caregivers and support workers.

The clinic is on **Thursdays from 4:00 p.m. to 7:45 p.m.** The cost is \$13 for people with Parkinson's and \$22 for carepartners and support workers.

We have received excellent feedback from those who have attended the clinic. If you are interested, please call the clinic receptionist at **604 520 1830**.

Access is through the back entrance on Clarkson Street and is wheelchair accessible.





Buying drugs over the internet

If you buy drugs online, you may be putting your health at serious risk. This is especially true if you order prescription drugs without being examined in person by a healthcare practitioner.

A simple Internet search will turn up hundreds of websites that sell drugs. Some Internet pharmacies are legitimate, but many offer products and services that are dangerous. Some sell drugs that are not approved for use in Canada because of safety concerns. Some take advantage of people desperate for relief by offering “miracle cures” for serious illnesses like cancer. Many offer prescription drugs based on answers to an on-line questionnaire. These sites tell you they will save you the “embarrassment” of talking to your doctor about certain prescription drugs, such as Viagra, or drugs to prevent hair loss, or promote weight loss. What they do not tell you is that it is dangerous to take a prescription drug without being examined in person and monitored by a healthcare practitioner to make sure the drug is helping you.

Risks associated with buying drugs online

Buying drugs from Internet pharmacies that do not provide a street address and telephone number may pose serious health risks. You have no way of knowing where these companies are located, where they get

their drugs, what is in their drugs, or how to reach them if there is a problem. If you order from these sites, you may get counterfeit drugs with no active ingredients, drugs with the wrong ingredients, drugs with dangerous additives, or drugs past their expiry date. Even if these drugs do not harm you directly or immediately, your condition may get worse without effective treatment.

If you order prescription drugs without being examined and monitored by a healthcare practitioner, you may be misdiagnosed, and miss the opportunity to get an appropriate treatment that would help you. You may also put yourself at risk for drug interactions, or harmful side effects that a qualified health professional could better foresee.

Buying drugs on the Internet may also pose financial risks. In some cases, the product may not be shipped at all, or if it is coming from another country, it could be stopped at the border by Canadian authorities.

The status of Internet pharmacy in Canada

A number of pharmacies in Canada have legitimate websites that offer a limited range of products and services, including information for consumers, and shopping for certain items. The practice of pharmacy in Canada is regulated by the provinces, and any licensed pharmacy that offers Internet services must meet the standards of practice within its own province.

If you have questions about whether an Internet pharmacy is legitimate, contact the licensing body in your province or territory.

Minimizing your risk

Do not take any prescription drug that has not been prescribed for you by a healthcare practitioner who has examined you in person.

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Do tell your doctor and pharmacist about all of the health products you take, including vitamin and natural health products, as well as prescription and over-the-counter drugs. They need this information to assess and advise you about potential side effects and drug interactions.

If you decide to order drugs online:

Do not do business with a website that:

- refuses to give you a street address, telephone number, and a way of contacting a pharmacist;
- offers prescription drugs without a prescription, or offers to issue a prescription based on answers to an on-line questionnaire;
- claims to have a “miracle cure” for any serious condition; or
- sells products that do not have a DIN (see below) issued by Health Canada.

Do make sure you are dealing with a Canadian-based website that is linked to a “bricks and mortar” pharmacy that meets the regulatory requirements in your province/territory.

Finally, if you have a question or complaint about therapeutic drug products purchased online, call Health Canada’s toll-free hotline: 1-800-267-9675

Health Canada’s role

Health Canada regulates therapeutic drugs in Canada through a rigorous licensing process, which includes

an extensive pre-market review and the ongoing post-market assessment of a drug’s safety, effectiveness and quality. As part of this process, Health Canada conducts risk/benefit assessments, monitors adverse reactions, and communicates information about risks to health professionals and the public. All drugs approved for sale in Canada have an eight-digit Drug Identification Number (DIN). The DIN assures you that Health Canada has assessed a drug, and considers it safe and effective when used as directed on the label. The DIN also provides a way to track adverse drug reactions.

Health Canada licenses and conducts regular inspections of companies that manufacture, import and/or distribute drugs. In addition, Health Canada investigates complaints related to the sale or use of therapeutic drugs, including complaints about websites that sell drugs, and takes action where appropriate. Also, Health Canada works with the Canada Customs and Revenue Agency to control the illegal entry of prescription and over-the-counter drugs. Individual Canadians are allowed to import a three-month supply of therapeutic drugs, subject to a number of restrictions.

Health Canada. (2012). *Buying drugs over the internet*. Retrieved from Healthy Canadians, Government of Canada website: <http://www.healthycanadians.gc.ca/drugs-products-medicaments-produits/drugs-medicaments/internet-eng.php>

DO YOU HAVE PARKINSON’S RELATED LEGAL ISSUES?

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.

Guilty or Not

BY LESLIE DAVIDSON

Our house is for sale and we are moving to be near our children and grandchildren. I have just finished cleaning out the little building at the end of our driveway. It isn't a garage but more of a shed or shop, complete with a workbench and an ancient wood-burning stove. It has been a catch-all for our active family's outdoor stuff—gardening implements, sports equipment, woodworking tools and camping gear, all in multiples, because my husband, Lincoln, never threw away anything. When a ski pole broke he kept its partner, "just in case". In with a new bike did not mean out with the old. Ever. The same applied to skis, snowboards, backpacks, snowshoes, kayaks, paddles, wet suits, lifejackets, camping gear, tarpaulins, chains, rope, lawn chairs, air mattresses, tennis racquets, bocce balls, croquet mallets and hockey sticks. Lincoln never met a bungee cord he didn't love, or a broken tool that he could bear to toss. In my husband's world, duct tape fixed everything. But some things are not fixable, and Lincoln has no idea that his shed is being readied for the stuff of another family's life. He lives in a cottage in a long-term care residence along with 13 other advanced dementia patients. Though I have long grumbled about the state of that shed, I found the act of culling its 34 years' worth of accumulated contents incredibly difficult.

"Lincoln would be so upset if he could see all this being given away," I told a friend. "I feel so guilty".

I expected her response to be empathetic and reassuring. She is that kind of person. However, she did not say, "He would understand" or "This must be very difficult for you."

"Hmmm," she mused. "What do you think guilt is?"

I didn't know how to respond. She rephrased her question.

"You say it makes you feel guilty to have cleaned out the shed. I wonder how you define guilt? That's all."

After thinking about it for a moment, I told her I thought guilt was an emotion experienced when we have wronged another and know it. It was what my mother would have called "your conscience talking."

My friend then wondered aloud if guilt was of any use. I suggested that if it leads to a sincere apology and an attempt at making it right, followed by a heartfelt promise not to repeat the action, it is useful. It's a simple drill I told her. If you screw up, say you're sorry and mean it. Then, try to fix it and don't do it again.

"And so why is it wrong to be clearing out the shed?" she asked.

My turn to "hmmm."

As a caregiver, I have been, by my own definition, guilty of any number of things, mostly impatience. Wrapped up in my own despair, I know I failed to understand the devastating effects that his dementia was having on Lincoln's ability to feel safe or at ease in the world. It was his grace and patience that taught me hard lessons about compassion and acceptance. The PD beast had lessons for me, too. I fed it on stress and fatigue and it grew quickly. I started vomiting up my meds and was too weary to exercise. I looked in the mirror and I could not recognize the haggard old woman looking back at me. I shook and wobbled and made the good people in our lives anxious on my behalf. If I wanted to be the caregiver that Lincoln deserved, I needed to be strong and healthy, resilient. I needed to ask for help. And so I did. Guilt had served its purpose.

"What if they find a cure for Lewy-Body dementia tomorrow," I worried, "and I get to bring Lincoln home. What is he going to do when he sees what I have done to his shed?"

It was an image both cringe-worthy and joyous. It made us laugh, the kind of laughter that lives one breath away from tears. However, I am not going to be bringing Lincoln home but my feelings about the

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culling of the shed did not seem to quite fit my notion of guilt. There would be no easily recited “drill” for getting through this.

I told myself that it was just stuff in that shed, possessions, objects, all replaceable, but it was stuff that spoke about our whole family. It was stuff that represented how enriched my life and our children’s lives had been because of Lincoln’s passion for the outdoors and his willingness to share it with the people he loved. It was the stuff of memories.

Cleaning out the shed, even with the help of our supportive tribe of friends, meant that I was now on my own, alone in a way I have never been before, responsible for every decision affecting us both. I was forced into an independence I never wanted and that, if I am honest, frightened me. It still does. Feeling guilty was a whole lot easier than plumbing the depths of sadness that clearing out the stuff of our lives evoked in me. Feeling guilty meant I did not have to acknowledge the many joys of my life, when all I wanted to do was howl. It wasn’t just guilt at all, but a complex tangle of emotion, painted the colour of sorrow, in which guilt was just one tiny thread.

“You have to look after yourself!”

I hear that once a week, if not more. I know the truth of that assertion. I get that it comes from a place of kindness and caring. But sometimes it makes me want to explode with frustration.

“Don’t you think I know that!?” I want to shout. “Why do you think my husband is in a long-term care facility? Do you have any idea how that feels? Please don’t tell me what to do.”

How can anyone else know, for me, where necessary self-care ends and selfishness begins, when I hardly know it for myself?



My friend is wise and she has spoken with many caregivers. She tells me I am not alone in my frustration and confusion. She knows how consuming a misplaced sense of guilt can be when we fail to manage the unmanageable. She understands how disloyal we feel when making the hard decisions, hopefully in our loved one’s best interests, and our own. She tells me we are all trying to figure out how to tease out, from a huge tangle of emotions, the ones that are best to guide us, the ones that will hold us together as our worlds shift and crack. Empathy

and reassurance. She is that kind of person. And we agree that guilt has its place in our emotional lives but it is a place we too easily find. If we permit guilt to suspend our experience of our most profound pain, do we also allow it to diminish our capacity for joy?

And so I don’t shout. I smile and nod and carry on. It isn’t courage nor is it a lie. I am the only face of the twosome that once was Lincoln and Leslie, before Parkinson’s, before dementia, that most people ever see now. I try to see their concern for me as concern for us both. Our lives have changed and people care. That’s what “Look after yourself” infers. No, they don’t know what I am going through... any more than I am privy to the hard truths of their lives. And so I don’t shout. I dig into that tangle of emotion and I find, along with the anger and the regret, the grief and the guilt, a bright thread of gratitude. I cling to that. I have that choice.

Davidson, L. (2015, April). Guilty or Not. *On the Move, Volume 11*, pp. 14-15.

Join us along with family and friends for Parkinson SuperWalk



Keep moving to improve this September by registering for one of over 20 walks across British Columbia. Gather your family, friends and colleagues to form a fundraising team. Together we can support critical research and provide essential programs to help 12,500 individuals living with Parkinson's in BC.

Parkinson SuperWalk is the single most important awareness and fundraising event for Parkinson Society British Columbia and Regional Partners of the Parkinson Society Federation.

You are the everyday heroes of Parkinson's disease. You have the power to build extraordinary hope. Register now for a Parkinson SuperWalk near you!

June

17 & 24

Voice & Swallow Seminar – Burnaby

This two-day event will focus on the voice and swallowing challenges faced by people living with Parkinson's. It will be an interactive and participatory format and all levels of voice and swallow disorder will be included.

Date: Wednesday, June 17 & Wednesday, June 24

Time: 10:00 am – 3:00 pm (registration begins at 9:30 am)

Place: Accent Inns
3777 Henning Drive
Burnaby

Cost: \$40 Members
\$50 Non-members

Wednesday & Wednesday

September

22, 25 & 28

PWR!Community Talks with Becky Farley, PT, MS, PhD

Save the date for these upcoming community talks on Parkinson's Wellness Recovery (PWR!) led by Dr. Becky Farley.

Dates: September 22 – Community Talk Vancouver

September 25 – Community Talk Fraser Valley

September 28 – Community Talk Victoria

Community talks will offer information on how to optimize brain health and learning, as well as provide tools to better address the motor, cognitive and emotional symptoms of Parkinson's disease (PD). The sessions are based on the most recent research-based evidence that advocates for exercise as a first line of defense in PD.

Tuesday, Friday & Monday



Registration information can be found at www.parkinson.bc.ca/education-events

SuperWalk Locations in BC

Tuesday, September 8

- CHILLIWACK – Evergreen Hall

Saturday, September 12

- CRANBROOK – College of the Rockies track
- ELK VALLEY – Senior's Drop In Centre (Sparwood)
- INVERMERE – Pothole Park
- KAMLOOPS – Riverside Park/ Rotary Bandshell
- KELOWNA - Waterfront Park/ Concession Plaza
- PARKSVILLE – Parksville Community Park

- PITT MEADOWS/MAPLE RIDGE – Spirit Square (Pitt Meadows)
- PRINCE GEORGE – Fort George Park by the picnic shelter
- QUADRA ISLAND – Rebecca Spit Marine Provincial Park
- RICHMOND – Minoru Park running track
- VERNON – Polson Park
- VICTORIA – Esquimalt Gorge Park

Sunday, September 13

- CHASE – Chase Memorial Park
- FRASER VALLEY – The Fort Pub (Fort Langley)
- NELSON – Rotary Lakeside Park
- OLIVER – Oliver Community Centre

- SURREY – Bear Creek Park/Bear Creek Pavilion
- VANCOUVER – Stanley Park at Ceperley Playground

Monday, September 14

- BURNABY – Confederation Park track

Saturday, September 19

- SALMON ARM – McGuire Lake Park

September TBA

- COURTENAY/COMOX
- DUNCAN

SPONSOR



To have a pledge form mailed to you, or for more information about SuperWalk, contact Parkinson Society British Columbia at 604 662 3240 | 1 800 668 3330 | events@parkinson.bc.ca

Wednesday & Thursday

23 & 24

PWR! Instructor Training and Certification Workshop with Becky Farley, PT, MS, PhD

This course is suitable for professionals holding a current nationally or provincially recognized certification, including fitness trainers, group fitness instructors, yoga instructors, pilates instructors, dance instructors and individuals holding a minimum 2-year Associates Degree in health, exercise science or recreation. Physical therapists, physical therapist assistants, occupational therapists and occupational therapist assistants are also welcome to attend.

Dates: Wednesday, September 23 & Thursday, September 24

Place: Fortius Sport & Health
3713 Kensington Avenue
Burnaby

PWR! Instructor Training has been approved through the BC Recreation and Parks Association for 15 BCRPA CEC's.

Saturday & Sunday

26 & 27

PWR! Therapist Workshop with Becky Farley, PT, MS, PhD

This workshop is suitable for Physical/ Occupational Therapists and Physical/ Occupational Therapist Assistants.

Dates: Saturday, September 26 & Sunday, September 27

Place: G.F. Strong Rehabilitation Centre
4255 Laurel Street
Vancouver

VIEWPOINTS

Thank you to everyone who participated in helping to promote Parkinson's Awareness Month this past April. We are overwhelmed by the positive response from the Parkinson's community. Your fundraising efforts for The Parkinson's Movement have resulted in over \$31,500 in donations to help us develop and provide much needed exercise programs. **Help us keep The Movement going to reach our \$80,000 goal!**

YOUR DONATIONS ARE STILL NEEDED. To contribute or participate, visit www.parkinson.bc.ca/Parkinsons-Movement or call 1 800 668 3330.

Check out a few of the great stories from our community to help provide some exercise inspiration.



The Parkinson's Movement
Parkinson Society British Columbia

4 Peaks 4 Parkinson's with Just Giver 4PD Cycling Club

Spearheaded by long-time PSBC supporter, Kelly Jablonski, over 90 cyclists rode together on Sunday, May 3 to conquer the four peaks. The group cycled up SFU, Seymour, Grouse and Cypress, raising over \$3,100! We are grateful to this dedicated group of individuals who came together to make a difference in the lives of those living with Parkinson's.



Special thank you to the sponsors of The Parkinson's Movement:



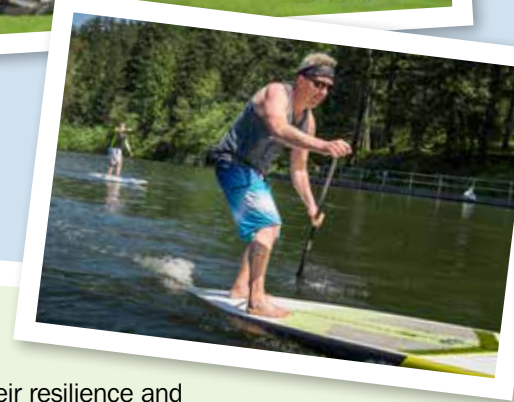
Pull for Parkinson's Club

Pull for Parkinson's is an annual ultimate frisbee tournament organized by high school students on the Lower Mainland. This year, twelve teams participated to raise over \$2,700 for Parkinson Society British Columbia. The event took place at Newton Athletic Park in Surrey on May 1. Thank you to this energetic and inspirational group of students for organizing such a successful and meaningful event!



Paddle 4 PD

Having worked with people living with Parkinson's disease for many years, Doug Pickard continues to be inspired in seeing their resilience and perseverance. In May, Doug committed to paddleboard 50 kilometers from Comox Harbour to Qualicum Beach to raise funds for Parkinson Society British Columbia. Doug considers himself lucky to have made a career out of helping people exercise and stay healthy. "I have seen the positive changes that exercise has on people's lives, especially those with PD. If you have PD, socializing with others who are going through similar experiences will help you realize that you are not alone. Spread enthusiasm and joy. Try not to dwell on the negative aspects of the disease, but rather do what you are able to do, and do it with vigour and purpose."



Parkinson Society British Columbia wishes to thank Doug for his continued support.

 Parkinson Society British Columbia
 Société Parkinson Colombie-Britannique

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