



# VIEWPOINTS

## Summer 2022

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by Parkinson Society  
British Columbia

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## Your support is essential.

Parkinson Society BC would not exist without the support of our members, donors, and volunteers.

## 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.

## Here are a few of the ways you can support the Society:

### MEMBERSHIP

For an annual fee of \$25, your household benefits from unlimited access to our education and support services, events, and resources.

### DONATIONS

Contact us to set up monthly, quarterly or annual donations, or think of us when giving through United Way.

### PLANNED GIVING & BEQUESTS

Consider Parkinson Society British Columbia as a beneficiary in your will.

### FUNDRAISING

Become a Champion for Parkinson's by organizing your own event benefiting the Society. For more information on how you can support us, visit [www.parkinson.bc.ca/donate](http://www.parkinson.bc.ca/donate).

### SUPPORT GROUPS

100 Mile House, Abbotsford, Advanced Carepartner Online, Burnaby, Campbell River, Carepartner Bereavement Online, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, Cranbrook, Duncan/Cowichan Valley, Early-Mid Stage Carepartner Online, Gabriola Island, Kamloops, Kelowna, Kelowna Carepartners, Kootenay Lake East Shore, Langley, Langley YOPD, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Nanaimo, Nanaimo Carepartners, New Diagnosis, New Westminster, North Shore, Osoyoos/Oliver, Parkinson's Online, Parksville/Qualicum, Parksville/Qualicum Caregivers, Port Alberni, Powell River, Prince George, Princeton, Quesnel, Richmond, Richmond Carepartners, Surrey, Trail/Castlegar, Tri Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Carepartners, Vancouver Downtown, Vancouver West Side, Vernon, Vernon Caregivers, Weekly Parkinson's Online, White Rock Carepartners, Williams Lake, Young Onset Parkinson's Online

### EDITORIAL STATEMENT

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

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# Research

## Cerebellar transcranial ultrasound stimulation to alleviate freezing of gait in Parkinson's disease

*Reproduced with permission from Parkinson Canada.*

Treatments to help people with Parkinson's disease (PD) whose gait freezes when they walk or pass through doorways have had limited success so far. To restore people's independence and freedom of movement, Dr. Jean-Francois Nankoo, a post-doctoral fellow at Toronto's University Health Network, is trying a new approach.

He's using low-intensity sound waves from an ultrasound machine to target the cerebellum, an area of the brain that appears to be involved in freezing. By focusing the sound waves directly on the back of the head where the cerebellum resides, Nankoo believes he can stimulate cells in that area of the brain that are already working hard to compensate for the damage Parkinson's has done.

*"The cerebellum tends towards being a corrector of movement," says Nankoo. "We think that in those people (with freezing of gait), this area of the cerebellum is increasing its activity, trying to correct some sort of malfunction."*

Nankoo believes the focused ultrasound waves will give the target cells an extra boost to help unfreeze people's gait. To test his theory, Nankoo will place a small, portable ultrasound on the back of the heads

of people who experience freezing of gait. He'll stimulate the cerebellum for one to two minutes. After the painless procedure, Nankoo will measure people's gait as they walk around, charting any improvement in freezing.

If Nankoo's treatment successfully unblocks freezing of gait, even for a short period of time, his research will span larger clinical trials. He'll then go on to investigate how long the sound wave stimulation should last, and how frequently it must be re-applied. Eventually, he hopes researchers could create a small, portable ultrasound for treatment in doctor's offices or even at home.

Nankoo was drawn to research involving Parkinson's because he realizes how central movement is to the basic human experience. "It's very important to me to resolve this issue that some patients cannot move, or have difficulty moving, or their body is not moving in the way they want to move," he says. If Nankoo's ultrasound treatment is successful, people with Parkinson's could regain more independence and experience a better quality of life, he says.

Receiving this Basic Research Fellowship is critical to Nankoo's dream of establishing a lab to develop this and other methods of treating Parkinson's, he says. He hopes the grant will also help him obtain a faculty position, "because it shows that I was able to secure some funds and my project had value, that there is a need for this type of research."

He encourages people to continue to support Parkinson's research, despite feeling that it is taking too long to generate new treatments or even a cure. The sole reason research has not advanced more quickly is lack of funds, Nankoo says.

"The more funds we have, the quicker we will resolve this situation. Carrying out these experiments is expensive, and I'm lucky enough to get the funds, but there are a whole bunch of other researchers that have equally great ideas, and that's how science works," he says. "We need multiple people to be trying to find a solution to a common problem. The funding is critical. I can't overstate that."



### RESEARCHER

Dr. Jean-Francois  
Nankoo

### INSTITUTE

University Health  
Network

### PROJECT GRANT

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

# Ask an Expert

## Dr. Omesh Kulkarni discusses how people with Parkinson's can make the most of their neurology appointments



**Dr. Omesh Kulkarni, MD**, is a neurologist specializing in Parkinson's disease (PD), serving mid to north Vancouver Island. After completing medical school in India, he trained as a neurologist in England, followed by a year as a fellow at the Parkinson's Disease and Movement Disorders Center at the Beth Israel Deaconess Medical Center in Boston, Massachusetts. After his fellowship, he started a Parkinson's and Movement Disorders clinic in England, which ran from 2013 to 2021. Presently, Dr. Kulkarni works between two sites in Nanaimo – the Parkinson's and Movement Disorders Clinic at Nanaimo Regional General Hospital, and a private clinic.

### How does a person with Parkinson's disease access a neurologist's services in BC?

Family physicians play a vital role in the delivery of healthcare. By and large, they are the first port of call for all medical concerns. Family physicians are well-placed to decide when and where to refer. They usually have a good idea of local specialists and their sub-specialty interests. The best way for patients with suspected or confirmed Parkinson's disease to access a neurologist is to liaise with their family doctor and seek a referral.

People with Parkinson's may sometimes relocate to be closer to their loved ones. This creates the added stress of finding a neurologist with a Parkinson's disease specialty in their new community. In most cases, this can be mitigated by asking their existing neurologist to refer them to the nearest Parkinson's clinic. Vancouver Island now has two Parkinson's clinics – one in Nanaimo, and the other in Victoria.

### What can people with PD expect at their first neurologist appointment?

To begin, patients can expect their neurologists to ask about their current troublesome symptoms. Prior health issues, as well as any current medications and those previously tried, will also likely be reviewed. This is then followed by a focused examination. Your neurologist is trying to put together everything, like a jigsaw puzzle, to arrive at a diagnosis. The second half of the consultation is mainly devoted to discussing the diagnosis, counselling, and chalking out a plan of action, which, in the majority of people, is commencing dopaminergic medications to try to alleviate symptoms.

You can expect to be given verbal information, as well as printed materials, to empower you and help with future decisions. I recommend patients take home as much written information as possible. The first appointment can be overwhelming and patients may not remember everything discussed. Where available, you may also be introduced to the clinic's Parkinson's nurses and other team members.

### How often should a person with PD see their neurologist?

In some ways, this is dictated by the stage of Parkinson's. People in the early stages of PD are less likely to need frequent medication changes. Whilst there are no strict guidelines, I believe follow-up every 6 to 12 months should be sufficient in the early stages. As Parkinson's progresses, patients require more frequent fine-tuning of medications, which then warrants more frequent follow-up.

### What information should a patient come prepared with to a neurology appointment?

Preparation depends on whether the appointment is a first visit or a follow-up. During the initial appointment, your neurologist will want to know if you have a family history of medical and/or neurological problems, so check with your family members prior to the appointment. Where possible, bring your loved one who knows you and your health issues well.

It is also important for patients to plan ahead and keep a running list of questions and concerns, which may help them feel better prepared. Remember that only you know your symptoms and concerns. Be prepared to provide your neurologist with information on your current problems and any background health issues. Ensure you also bring an up-to-date list of medications you are taking and their dosages. Please note, some clinicians work at more than one clinic. Make sure you have the correct address and leave plenty of time for parking.

### **When should a person with PD contact their primary care physician versus their neurologist?**

Family physicians have a fair idea of Parkinson's disease. They can address common issues, so contact your family physician first. If your family physician cannot address a particular problem, they will contact the neurologist to seek further advice. However, if your questions are related to advanced therapies like Deep Brain Stimulation (DBS) or Duodopa, or if you are running into troublesome motor fluctuations in the form of medications not lasting long enough or not kicking in on time, you may wish to get in touch with your neurologist first. Again, there are no strict rules regarding this. It is worth noting that you are likely to see your family physician quicker than your neurologist.

### **How can people with PD get the most out of their neurologist appointments?**

Before the appointment, where possible, sit down with your loved ones and write down a list of questions, concerns, and troublesome symptoms. Make sure you have an up-to-date list of medications you are taking. It is a good idea to keep track of when medications wear off prematurely or take too long to start working, as well as any dyskinesias. It is also worth spending time reading about Parkinson's, which can help you understand which symptoms are and are not Parkinson's-related. This will help you and your neurologist spend the maximum amount of time discussing the appropriate issues.

Arrive a few minutes early for your appointment. This gives you enough time to fill out intake

forms for the clinic and collect your thoughts ahead of the appointment. If it is a follow-up, update your neurologist about any new developments in your health or new medications since the last appointment. Go through your list of concerns and have them addressed. However trivial they might sound, if you are concerned, bring it to the attention of your neurologist.

Please make sure you tell your neurologist if you take any over-the-counter and/or herbal medications. Ask about the intended benefits and side effects of any prescribed medications, as well as how to address side effects, should they occur. You can also ask for medication refills. Be sure you have understood the treatment plan before you leave. If unsure, ask for clarification. Finally, obtain your neurologist's office contact information for any future inquiries.

### **How can caregivers/carepartners support people with PD before and during their neurology appointments?**

Caregivers play a vital role in the care of people with PD. It is worth noting that Parkinson's disease is a dynamic condition and the care, support, and involvement of caregivers is subject to change with time. They can help as much or as little as needed. Since most caregivers are spouses and family members, they tend to have a good idea about a patient's abilities and care needs.

At home, caregivers can be a source of company, engaging patients in conversations. Where needed, they can help with activities of daily living. They may also help take the person with PD to social gatherings, support groups, and medical appointments. In addition to keeping a schedule for the timely intake of medications, caregivers can help document responses and side effects.

During neurology appointments, caregivers can help patients convey their concerns if there are difficulties with speaking. They can also take notes and tell the neurologist about any benefits and side effects of medications.

### **What symptoms or changes warrant immediate attention from one's neurologist?**

Parkinson's disease is a condition that progresses slowly. The majority of patients are unlikely to

have Parkinson's-related emergencies that would require urgent attention. But please remember, if you cannot cope, your symptoms are severe and intolerable, and you feel seriously unwell, call 911 and seek urgent help whilst waiting for your neurologist to get back to you.

Severe swallowing issues that prevent you from taking medications need urgent attention. In this case, medications may need to be delivered via another route, like a nasogastric tube.

Repeated doses of Levodopa failing to produce a clear benefit, coupled with worsening stiffness, slowness, and tremor also need urgent evaluation to uncover the underlying cause (such as severe constipation, pain, a change in diet, etc.).

Sudden dramatic worsening of PD symptoms in someone on an advanced therapy, like DBS or Duodopa, requires immediate attention, as this could be a failure of the DBS circuit or displacement of the Duodopa tube.

#### **MOTOR EMERGENCIES:**

- Recurrent 'off' periods: severe tremor, pain, profuse sweating, and/or tachycardia
- Parkinsonism-hyperpyrexia syndrome: when dopaminergic medications do not produce the desired benefit, combined with high fever, feeling unwell, and unusual excessive stiffness and/or slowness
- Dyskinesia-hyperpyrexia syndrome: severe uncontrollable persistent dyskinesias, or what looks like a dyskinetic storm

#### **NON-MOTOR COMPLICATIONS:**

- Acute psychosis: paranoia, agitation, severe confusion, and/or hallucinations
- Impulse control disorders: abnormal behaviors like gambling, excessive shopping, and/or hypersexuality

#### **If you were a person with Parkinson's, what questions would you ask your neurologist?**

I'd start with the million-dollar question: when is the cure coming out? Following that, I would be interested in my neurologist's thoughts on these issues:

- Do I need medication (upon diagnosis)?
- What is the rate of progress I can expect?
- Is there anything I can do to slow down the progression?
- What is the role of exercise in treating PD?
- Am I being optimally treated, or can something in my care plan be modified?
- Is there anything I could be doing to improve my symptoms?
- What can I expect with medications?
- What are the side effects of medications?
- Can I continue to drive?
- Am I eligible for advanced therapies?
- What are the pros and cons of taking part in research trials?

#### **ADDITIONAL RESOURCES**

- **ParkiTrack**  
[www.parkinson.bc.ca/parkitrack](http://www.parkinson.bc.ca/parkitrack)
- **Preparing for a Medical Appointment**  
<http://bit.ly/pdappointmentprep>
- **Comprehensive Care Plan Checklist (for tracking symptoms)**  
<http://bit.ly/comprehensivechecklistpd>
- **Talking to Your Healthcare Professionals**  
<http://bit.ly/talkingtohealthcareprofs>
- **Your Healthcare Team and How to Access It**  
<http://bit.ly/pdhealthcareteam>

# Living Well

## Overcoming stigma with self-compassion



Erving Goffman, prominent twentieth century sociologist and social psychologist, defined stigma as “the situation of the individual who is disqualified from full social acceptance” (Goffman, 1963). In other words, stigma occurs when someone is labelled and discriminated against, because they have characteristics that some members of society have deemed undesirable (Eccles, et al., 2022). Individuals with neurological conditions and other physical limitations may be especially vulnerable to stigma due to the visible nature of their illnesses. Misunderstandings by the general public further compound issues around stigma, as is the case with people with Parkinson’s disease (PD). While many people have heard of PD, fewer understand the diversity of symptoms that people with PD may experience and, as a result, may misattribute the symptoms to other causes.

Stigma can arise from the actions and attitudes of others, known as “enacted stigma”, or from one’s own internalization of negative stereotypes, called “felt stigma” (Eccles, et al., 2022). The characteristics associated with experiencing greater felt stigma for people with PD are younger age, especially in men, and depression, regardless of gender (Salazar, et al., 2019).

### THERE ARE SEVERAL MAJOR SOURCES OF STIGMA EXPERIENCED BY PEOPLE WITH PD, INCLUDING:

- 1. Stigma due to symptoms:** the symptoms of Parkinson’s are often observable and, as a result, may lead to misunderstandings and incorrect labelling. For example, a tremor or unsteady gait may be misinterpreted as a sign of intoxication. Furthermore, the loss of autonomy and increasing dependence on others that can accompany advancing stages of PD may also result in felt stigma (Maffoni, et al., 2017).
- 2. Stigma due to communication difficulties:** many people with Parkinson’s experience communication challenges, which may lead to feelings of frustration, as well as both enacted and felt stigma (Maffoni, et al., 2017).
- 3. Stigma due to self-perception:** as the disease progresses and people with PD require more external help from caregivers, felt stigma may increase if the person with PD feels like a burden. Changing social roles, such as leaving one’s career for health reasons, also have the potential to increase felt stigma (Maffoni, et al., 2017).

Stigma is a major concern for people with PD, as it has large implications for mental wellbeing. Experiences of stigma are correlated with higher anxiety, stress, and depression among people with PD. Research even suggests that people with Parkinson's may experience felt stigma without directly experiencing enacted stigma; this suggests that people with PD sometimes internalize negative stereotypes about themselves (*Eccles, et al., 2022*).

However, self-compassion is a powerful tool that can help people with PD persevere in the face of stigma. Self-compassion is defined as nonjudgmental acknowledgment of one's own experiences, with an emphasis on kindness, concern, and support. It is an important way to regulate emotions, boost wellbeing, and self-soothe. Individuals with higher self-compassion may be able to more objectively assess interactions with others, as well as positively reframe situations in which they experienced enacted stigma, which can reduce distress and increase feelings of safety. People with PD with higher self-compassion also internalize negative stereotypes about themselves less frequently (*Eccles, et al., 2022*).

Increasing public awareness and visibility of people with Parkinson's is important to help improve public understanding of PD and its presentations (*Eccles, et al., 2022*). That is why advocacy efforts and awareness campaigns are so important – they help to normalize the many expressions of PD, and bring to light that Parkinson's is a diverse condition that impacts no two people the same way. The Society also works tirelessly so that people with Parkinson's feel empowered with the tools and resources they need to self-advocate in challenging circumstances. We hear many stories from the community involving situations in which a person with PD faced unjust treatment.

One such story came from Norman, who experienced stigma as a direct result of his PD. While watching a group of female volunteers painting lines for visitor parking spots, a group of individuals misinterpreted Norman's Parkinson's

symptoms, such as tremor, reduced facial expression, and fixed gaze, as leering. In another instance, the same group thought he was loitering in a hallway, due to his reduced mobility. Someone wrote to the strata anonymously to express how uncomfortable they felt about Norman's presence.



When reflecting on these incidents, Norman says he felt very angry and hurt. Facing stigma of this nature made him self-conscious of how he interacted with anyone in his building. As a result, he reached out to Parkinson Society BC and his neurologist to get support. While the situations still remain in the back of his mind, Norman now feels he can continue with his day, knowing he has done all he can to speak up and inform others about his experience.

Another story came from Shelly, who faced stigma after ordering a pizza at a local pizza parlour. After placing her order, she returned to her Jeep to wait, when an RCMP officer approached her vehicle and asked if she had driven there. After she said she had, he demanded she sit in the police car and take a breathalyzer test. The pizza parlour employee had



reported Shelly as driving while intoxicated because of her hitched gait due to her Parkinson's. He told the officer that he smelled alcohol on her, even though she and the employee were both wearing masks. The parlour was situated in a very busy area, with plenty of foot and car traffic nearby. Shelly says she felt uncomfortable having the interaction in such a public place, but when she asked the officer if they could move to the nearby alley to speak, he curtly refused.

After the breathalyzer showed a blood alcohol level of zero, Shelly and the officer spoke with the employee. Shelly informed him she had Parkinson's, and took the opportunity to calmly educate the employee about the symptoms she

experiences because of the disease. He admitted the smell he reported was, on second thought, that of hand sanitizer. She says the employee seemed apologetic and ashamed after their interaction and hopes he will be more compassionate in the future. To help herself feel better, Shelly relied on her family and emotional support dog, and treated herself with kindness and self-compassion. Unfortunately, like Norman, Shelly now says that the incident has made her more mindful of how she presents in public with her Parkinson's.

It is clear that despite our best efforts, more public education and awareness are needed, so that members of the Parkinson's community can enjoy the safety that everyone deserves, both in their home and in public. Fortunately, there are things people with PD can do to boost self-compassion and help mitigate the effects of stigma. These include:

- **Psychological interventions, such as Acceptance and Commitment Therapy (ACT):** ACT encourages people to accept their thoughts and feelings in a nonjudgmental way, instead of resisting them (*Ackerman, 2022*). People with PD facing stigma could greatly benefit from ACT, as it could help them accept the things beyond their control and engage in actions that bring enrichment and joy to their lives (*Ackerman, 2022*).
- **Practicing mindfulness:** mindfulness techniques can allow us to gain insight into our thoughts through nonjudgmental observation. In fact, there is growing research into the field of mindful self-compassion, a technique that aims to help individuals cope better with painful experiences by boosting their empathy and kindness for themselves (*Mead, 2022*). Identifying and changing self-talk patterns is a key component of mindful self-compassion; individuals are encouraged to ask themselves, "how would I treat a friend in the same situation?" (*Mead, 2022*).
- **Using evidence-based resources:** the help of a qualified mental health professional can be invaluable for many. Others may prefer to work in a more self-directed format. There are many free, accessible resources available to increase self-compassion, including those found at [www.self-compassion.org](http://www.self-compassion.org).



Through Parkinson Society BC, several law firms offer free legal services to the Society, for issues such as discrimination, denial of services, and denial of disability insurance. For more information, please contact Jean Blake, CEO, at [jblake@parkinson.bc.ca](mailto:jblake@parkinson.bc.ca).

*Parkinson Society BC would like to thank Norman and Shelly for their candidness and courage in sharing the stories that are featured in this article.*

#### ADDITIONAL RESOURCES

- **Duty to Accommodate & Disability Insurance**  
Helpsheet: <http://bit.ly/pddutytoaccomodate>
- **Mindfulness and Parkinson's**  
YouTube video: <https://bit.ly/mindfulnessandpd>

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**LARRY, HENRY, AND REBECCA GIFFORD**  
LARRY WAS DIAGNOSED WITH YOUNG-  
ONSET PARKINSON'S DISEASE



## Our Mission

Empower people with Parkinson's in British Columbia through providing resources and services to enable self-management, self-reliance, and self-advocacy.

## What is Parkinson's Disease?

Parkinson's disease is caused by a loss of dopamine in the brain and is the second most common chronic neurodegenerative disorder after Alzheimer's disease. Both motor and non-motor symptoms may be experienced, such as tremor, rigidity, slowness of movement, difficulty with speech, sleep disturbance and mood disorders. There is currently no known cure.

It is estimated that there are approximately 15,000 individuals living with Parkinson's in British Columbia. Experts predict that the incidence of Parkinson's will double by 2040. While the vast majority of people with Parkinson's are over 60, 20% are diagnosed before the age of 50 and many are in their 30s and 40s.

# Executive Message

At Parkinson Society British Columbia, we know just how challenging this time has been for our community. Thanks to your generous support, here are some of the ways we are working to support our community:

- To help better navigate the support services and resources available, we increased our availability for information and referral consultations via phone and email. We also expanded our counselling service to accommodate more clients.
- Our educational events continued to be provided online; however, as provincial health guidelines allowed, we will provide some of our programs in person again.
- Offering new webinars every week, featuring expert speakers on topics like mindfulness, and self-management. We want to make sure our community stays informed and engaged in their Parkinson's care.
- Keeping our community socially connected by helping our support groups transition to phone and video chat meetings, and through initiatives like drumming and singing, and our hobby series.
- To help our community stay active, we offer a range of exercise programs.
- We updated our website with information on COVID-19 and supports available to the PD community during the outbreak. We provided resources for frequently asked questions, mental health and wellness tips, event and program listings, and online resources.
- Funding three projects on genetics and stem cell research through the Michael Smith Foundation for Health Research in BC, receiving their matching funding to double these research dollars.
- We also funded research, through Parkinson Canada's (PC) national research program including projects examining issues like freezing of gait, swallowing issues, gene therapy, and neuroimaging.

By supporting Canadian researchers to undertake leading edge research in Parkinson's disease, you are helping to work towards a cure and improved care.

Thank you for helping Parkinson Society British Columbia do even more than ever for British Columbians suffering from Parkinson's disease. Together we can unlock the mysteries of Parkinson's disease and find a cure.

Signed,



Jean Blake  
CEO



Andrew Davenport  
CHAIR

# Message from Finance Committee

The Statement of Financial Position for the year ended December 31, 2021 presents very healthy working capital with current assets significantly exceeding current liabilities. The Society's investment portfolio now has a market value of \$4,353,000 (2020 \$3,849,000) and generates modest returns.

Overall, the 2021 Statement of Revenue and Expenses presents an excess of revenue over expenses of \$507,000 compared to the 2021 budget that was approved with a planned deficit of \$630,000. Fundraising revenue, excluding bequests was \$1,083,000 and continues to be an important part of PSBC's financial well-being. We are grateful for the continued commitment and support of our event participants, volunteers, donors, and sponsors especially during this unprecedented time.

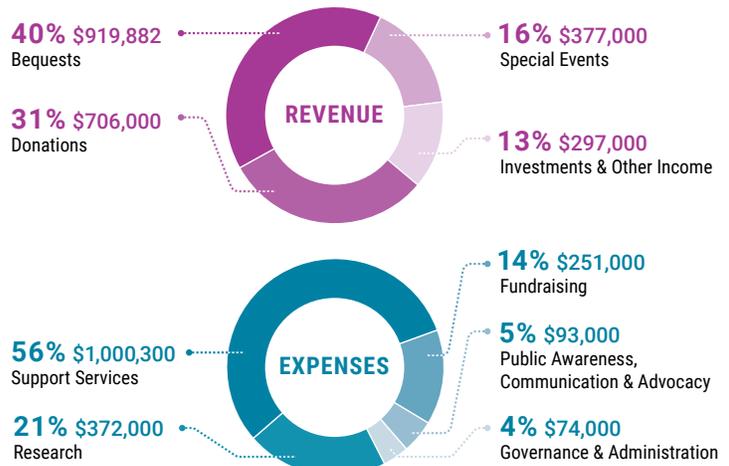
During 2021, the Board continued to invest in an innovative approach to advocacy by providing incentive funding to two health authorities for provision of a team approach in the Victoria and Kelowna Movement Disorder Clinics and began a similar investment with Vancouver Coastal Health Authority for the UBC Movement Disorder Clinic, adding a part time Occupational Therapist and part-time Speech Therapist. We are investing \$500,000 over five years (2020 – 2024; 2021 – 2026) to improve care in each of these health regions.

As well, we have committed to investing a \$455,000 in research in 2022 with additional commitments through to 2026. While we continue to fund research through the Parkinson Canada Research Program, we also partner with the Michael Smith Foundation for Health Research (MSFHR), which matches our research contributions.

The Society enters 2022 with reserves equal to 24 months of its historical expenses, which provides the Board with further opportunity to actualize our strategic priorities. The Board continues to review opportunities to further increase the Society's impact and reach throughout BC.

## Our Picture of Financial Accountability

To view a copy of our audited 2021 Financial Statements, visit [www.parkinson.bc.ca](http://www.parkinson.bc.ca)



# Our Year in Review

85



referrals from healthcare professionals through our PD Connect program

350



attendees at our virtual provincial conference, Moving Forward, Together

186



exercise, activity, and education webinars serving 4,635 participants\*

\*Total webinars including those that were part of a series.

\$295,020

raised for Parkinson SuperWalk



\$919,882

given from the estates of six individuals



2,566

information and referral calls and emails



802

hours of counselling

100

new counselling clients



147

in-depth consultations

## Other Achievements



Introducing a bereavement support group for caregivers



Supporting those with that have limited access to, or knowledge of, technology by offering resources by mail



Development of a new exercise booklet specifically for people with Parkinson's



Hosting virtual open houses for the community that provide an overview of the programs & services offered by the Society



Launch of the new virtual physiotherapy consultation service



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**Note:** We strive to ensure that each name is appropriately listed and spelled. Please let us know if we have made an error so we may correctly recognize you in the future.

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# Carepartner's Corner

## Intimacy and Parkinson's

Intimacy can mean different things to different people, and may include physical, emotional, and sexual connection with another person. Intimacy is an important part of a relationship, helping to foster trust, openness, and love. While Parkinson's disease (PD) may pose challenges to the expression of intimacy, especially that of a sexual nature, PD does not need to mean the end of one's love life. It is important to remember that there are many ways to express intimacy. By remaining flexible and creative, people with Parkinson's and their carepartners can experience fulfillment and joy in their relationships.

There are plenty of reasons to prioritize intimacy in any relationship, including enhanced connection, boosted mood, and improved wellbeing, but people with Parkinson's can add a few additional reasons to that list – research conducted on men in the early stages of PD found that those who maintained a healthy sex life were less likely to experience motor difficulties and depression, and were more likely to have a higher quality of life overall (*Picillo, et al., 2019*).

Larry and Rebecca Gifford personally know how staying adaptable and flexible can help keep the spark alive. The couple, who will celebrate 23 years of marriage this year, says that intimacy and closeness have been a fundamental part of their relationship, even before Larry was diagnosed with Young-Onset Parkinson's disease in 2017. "We know this aspect of our relationship is still very important, so we are putting in the time and energy to adapt and make it work as long as possible," says Rebecca.

However, they admit that incorporating intimacy into their lives is complicated by several factors, such as finding time away from their 12-year-old son and busy schedules. The symptoms of Parkinson's also mean that the window for when sexual intimacy is possible and comfortable for them is narrow. Larry lives with neuropathy, dyskinesia, balance issues, anxiety, and urinary issues. He is not alone in experiencing difficulty due to his PD – concerns

around sex and intimacy are prevalent among people with PD because of factors like pain, fatigue, depression, and motor symptoms. Common sexual function challenges, such as erectile dysfunction, low sexual desire, and hypersexuality, can also contribute to sex and intimacy issues.

Larry acknowledges that Parkinson's can create obstacles in sexual expression. Something that many people take for granted, like removing clothes with ease, or the ability to roll over and scoot to the center of the bed, can become difficult for individuals with PD. "As my symptoms progress and discomfort in my body increases, it is much less about sex and more about moments," he says.

However, it is not just the person with Parkinson's that may struggle with intimacy issues. "Your partner is dealing with Parkinson's too," says Larry. Carepartners may juggle many priorities, frequently assuming several roles in their partnerships and families. It is no surprise that being a carepartner, while often immensely rewarding, can put a damper on intimacy in a relationship. "Parkinson's does not take a time out for you to have a conjugal visit. If you are not exhausted by PD, your partner may be," he says. "Everyone wants to be cared for – do what you can do to care for your carepartner."

Transitioning into a carepartner role can bring about many changes for a relationship, including a role reversal, where the carepartner takes on some or all of the tasks their partner used to do (*Didyk, n.d.*). This may result in the relationship dynamic becoming more dependent, which shifts additional responsibility onto the carepartner (*Didyk, n.d.*). Grief and loss can also present challenges to the sexual health of a partnership (*Didyk, n.d.*). The multiple and incremental losses associated with Parkinson's can be a continual presence in the life of a carepartner. Carepartners may find it difficult to know their loved one is not the person they used to be, and may struggle to cope with the loss of dreams they once held for their retirement years together. As a result, carepartners experience a higher frequency of depression and anxiety, which may in turn affect their ability to experience desire. "Give yourself permission to grieve the losses, and then move

forward with new ways of remaining close," Rebecca says, noting that there can be renewed excitement and engagement in the relationship if the partners allow themselves to embrace their new normal.

Ultimately, at the heart of Rebecca and Larry's relationship lies the importance of communication. They admit that meaningful conversations help them strengthen their bond. Because the changes and challenges Larry experiences as his PD progresses make communication more difficult, the couple has to stay mindful about how and when they talk. "This means we have to throw out the effortless communication shorthand we'd had for most of our 20 years and patiently (and often impatiently) relearn how to connect," says Rebecca. "When we make or take the opportunity to have heart-to-heart, vulnerable, trusting conversations, they mean the world to us and are a crucial part of how we remain close."

Broadening their view of what intimacy is has also been immensely helpful for the couple. Finding pleasure in simpler things, like holding hands at a park, sharing habanero dark chocolate as an after-dinner treat, or not hesitating to bring out "the good bottle of wine" just because it is Tuesday, have given them a richness and vulnerability to their relationship. "We steal moments to embrace and kiss. We connect through coy smiles, double entendre, foot rubs, listening to 'our' songs, laughing about the ridiculousness of life and this disease, and sharing our highs and lows of each day," Larry says. "When we exchange looks, I can be 28 again."

*We know this aspect of our relationship is still very important, so we are putting in the time and energy to adapt and make it work as long as possible*

#### ADDITIONAL RESOURCES

- **Sexual Intimacy and Parkinson's**  
Helpsheet: <http://bit.ly/pdintimacy>
- **Carepartner Connect: Maintaining Sexual Intimacy While Coping with Parkinson's**  
Webinar: <https://bit.ly/carepartnerintimacypd>

#### SOURCES

- Didyk, N. (n.d.). Sex when caregiving: Navigating your changing relationship (even if there's dementia). Better Health While Aging. <https://betterhealthwhileaging.net/navigating-sex-when-caregiving-or-dementia>
- Picillo, M., Palladino, R., Erro, R. Colosimo, C., Marconi, R. Antonini, A. & Barone, P. (2019). The PRIAMO study: Active sexual life is associated with better motor and non-motor outcomes in men with early Parkinson's disease. *European Journal of Neurology*, 26(10), 1327-1333. <https://doi.org/10.1111/ene.13983>



# Newsworthy

## Upcoming Education & Exercise Events

### Virtual Gardening Group

Every 2nd & 4th Thursday,  
March 10 – September 22:

Linda Boehm

### SongShine

Thursdays, June 2 – July 7:

Joani Bye

### Getting Started with Writing Workshop Series

Wednesdays, June 22 – July 13:

Cristy Watson, Award-winning Author

### Dancing with Parkinson's

Tuesdays, July 5 – 26:

Megan Walker-Straight,  
Dance for PD® Certified

### PWR! Summer Mind & Body Fitness Class

Thursdays, July 7 – 28:

Gina Fernandez, Occupational Therapist

### Virtual Open House

August 16:

Liz Janze, Education & Support  
Services Coordinator at PSBC

### Move with Shelly

August (TBD):

Shelly Yu, Neuro Physiotherapist



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Thank you to the parent-teacher association at St. Francis Xavier for raising \$800 during their Krispy Kreme donut fundraiser!



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To view our full education event listings & register online, please visit:

[parkinson.bc.ca/events](https://parkinson.bc.ca/events)



## Save the Date

**Saturday, October 15th: Radisson Hotel, Richmond, BC**

Our provincial conference returns this October! Featuring presentations from prominent Parkinson’s specialists and researchers across the country, this year’s *Moving Forward, Together* will foster an educational and inspirational space for enriching the connection between people with Parkinson’s, carepartners, friends, and healthcare professionals.

The full-day conference will include two morning plenaries and eight afternoon breakout sessions, which offer a diversified itinerary for all attendees. This year, we are also offering a breakout stream specifically for healthcare professionals to attend and expand their knowledge of Parkinson’s disease.

**Mark your calendars, and stay tuned! Plenary speakers and topics include:**



### Dr. Alfonso Fasano

#### **Pain: The Invisible Symptom of Parkinson’s Disease**

Pain is experienced by up to 85% of people with Parkinson’s disease, yet is poorly understood and often overlooked. In this talk, Dr. Fasano will address the five main types of pain experienced by people living with Parkinson’s, as pain varies depending on the underlying causes and any comorbidities. Pain management strategies will also be explored.



### Dr. Penny MacDonald & Maggie Prenger

#### **Social Symptoms of Parkinson’s Disease**

In this talk, Dr. MacDonald and Maggie Prenger will provide an overview of the current research documenting the presence and distinct types of social symptoms that occur in people with Parkinson’s disease. They will explore how these symptoms impact the lives of people with the disease and their loved ones, as well as strategies for mitigating their effects.

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