



VIEWPOINTS

Spring 2022

VIEWPOINTS

Quarterly Newsletter
by Parkinson Society
British Columbia

3

Ask an Expert: Dr. Andrew
Howard Discusses
Problematic Anxiety

10

Carepartner's Corner:
Tools and Resources
for Caregivers

13

Newsworthy:
Upcoming Education
& Exercise Events

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

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Ask an Expert

Dr. Andrew Howard discusses problematic anxiety in people with Parkinson's



Dr. Andrew Howard, MD, FRCPC is currently a Clinical Associate Professor in the Department of Psychiatry at the University of British Columbia (UBC), and a

consultant neuropsychiatrist and clinical researcher involved with movement disorder patients at the Pacific Parkinson's Research Centre and the Centre for Huntington Disease at UBC. In 2021, Dr. Howard spoke at Parkinson Society BC's Annual General Meeting on the manifestations and complications of problematic anxiety in Parkinson's disease.

How common is anxiety in people with Parkinson's disease?

Anxiety is one of the most common psychiatric symptoms experienced by people with Parkinson's disease (PD). At any given point in time, one-third of people with PD are experiencing anxiety; this increases to 50% over the entire course of illness.

What are the common types and expressions of anxiety in Parkinson's disease?

Common types of anxiety in Parkinson's disease include panic attacks (unrelated to the timing of medication), episodic anxiety (which may be associated with the wearing off of dopaminergic drugs), persistent generalized anxiety, social anxiety and fear of embarrassment, and phobias (such as a fear of freezing, falling, or choking). Expressions of anxiety in PD frequently manifest as tension, restlessness, irritability, slow thinking, and/or poor concentration.

What are the risk factors for developing anxiety in PD?

Individuals with a personal or family history of anxiety and other related psychiatric conditions are at greater risk of developing an anxiety disorder.

PD-specific risk factors include a younger age of onset, faster rate of disease progression, greater disease severity, autonomic symptoms (such as difficulty regulating body temperature and heart rate), and REM sleep behaviour disorder, a common sleep disturbance experienced by people with Parkinson's. Motor fluctuations, such as end-of-dose effects, difficulty with medication kicking in, dyskinesia, and freezing episodes may also directly cause anxiety disorders. Individuals with PD who have less social support are at greater risk of developing an anxiety disorder. Furthermore, an avoidant personality, a tendency towards avoiding fear-provoking situations or activities, increases susceptibility to anxiety. This is because avoidance feeds fear and is arguably the most important disease-modifying variable in all anxiety-based conditions.

Is anxiety directly caused by Parkinson's, or is it a response to a loss of motor control?

Traditionally, anxiety has been viewed as a reaction to the physical manifestations of Parkinson's, as well as the difficulty of living with a progressive, degenerative condition. However, the latest research is challenging this assumption. There is evidence indicating that the neurodegeneration caused by PD not only affects motor circuits of the brain, but also areas involved in emotional processing, likely directly causing anxiety.

A study that utilized neuroimaging to examine the brains of individuals with anxiety and PD, noted an overlap between areas of the brain traditionally associated with fear and those impacted by Parkinson's. It also revealed a greater disruption of serotonin pathways. Serotonin is often known as the "happy chemical"; its depletion directly causes anxiety. Furthermore, when examined clinically, patients with an abrupt onset of motor fluctuations frequently reported increasing anxiety prior to the onset of the motor changes. Many also often reported anxiety in the early stage of the illness, before being diagnosed with Parkinson's. This evidence points to anxiety as a symptom of the disease, and less so as a reaction to the loss of motor control.

On the contrary, there is also evidence that loss of motor control may cause anxiety in some individuals with Parkinson's. A study demonstrated that PD patients with higher anxiety had decreased dopamine uptake at diagnosis, implying that they would be more susceptible to shifts in dopamine from the beginning of the disease, even before starting medication. Another study compared a Levodopa infusion to a placebo. It was found that the Levodopa infusion assisted with mood elevation and anxiety reduction. This indicates that for certain people with PD, managing Parkinson's symptoms may be effective at reducing anxiety.

It appears that whether anxiety is a symptom of neurodegeneration or a response to living with PD depends on the timing of its onset, and is best assessed by medical professionals involved in the management of the individual's disease. Determining the timing of its onset is important to ensure targeted, appropriate treatment.

What are some of the obstacles in treating anxiety in Parkinson's?

Despite its prevalence in people with PD, and relative ease for effective treatment, anxiety often goes untreated. There remains an assumption between healthcare professionals, carepartners, and patients that anxiety is always a byproduct of chronic disability, and that if patients are able to overcome the challenges they face as a result of their Parkinson's, the anxiety will resolve. This is a bias that we need to correct, as it does not consider the effect of neurodegeneration on the development of anxiety disorders.

In combination with this bias, the placebo effect commonly seen in the PD population makes it difficult to show the impact of a medication or intervention. Because this effect requires studies to be very large, there continues to be minimal research support and scientific evidence for proper assessment and management of anxiety in PD. This further reinforces the bias that the individual should manage anxiety on their own, as up until recently there have been few evidence-based guidelines for professionals and patients.

What therapeutic options exist to treat anxiety in Parkinson's?

Cognitive behavioural therapy (CBT) is recognized as the gold standard in treating anxiety, in combination with anxiety-reducing medications. CBT helps individuals limit or diminish avoidance and slowly do more of what they fear, rather than being controlled by what they imagine will be the worst outcome. CBT is most effective when carepartners are involved, as learning it helps them to better support their loved one. The evidence for CBT's effectiveness for people with PD is encouraging. A study of 48 Parkinson's patients, given either 10 weekly sessions of CBT or just clinically monitored with no exposure to CBT, showed that all subjects improved, demonstrating the common placebo effect amongst people with PD. However, those receiving CBT showed a reduction of 10 points on the Parkinson Anxiety Scale, a frequently used anxiety assessment tool, compared to just five points in the control group.

There are also alternative therapies available to treat anxiety, such as mindfulness and yoga. While there is limited data supporting the effectiveness of these therapies specifically for treating anxiety in people with Parkinson's, they are generally regarded as helpful for both physical and mental wellbeing.

What medications and medical options can help treat anxiety in Parkinson's?

To help manage anxiety, it is crucial that PD medication be optimized to minimize 'off' periods. This may be done with the use of extended-release medications, enzyme inhibitors, and dopamine agonist patches. It is important to note that anti-parkinsonian agents, such as Sinemet®, do not always improve anxiety and should not be relied upon for this purpose. Individuals will often increase their Sinemet® in response to motor fluctuations caused by anxiety, which can actually result in increased anxiety due to greater shifts in dopamine levels. Furthermore, these drugs may provoke anxiety when started initially in up to 20% of patients.

Many psychiatric medication options exist for treating anxiety in PD, particularly high dose SSRIs (selective serotonin reuptake inhibitors) or SNRIs (serotonin–norepinephrine reuptake inhibitors).

If CBT in combination with SSRI/SNRI treatment fails, antipsychotic medications may be a good next choice. This class of drugs is the most effective anti-anxiety medication prescribed by psychiatrists, but typically worsens the motor symptoms of PD. However, some antipsychotic drugs, such as quetiapine and clozapine, are effective at managing anxiety without worsening motor symptoms.

The use of benzodiazepines is typically discouraged for people with Parkinson's. Such drugs may cause sedation, cognitive impairment, and balance issues, as well as tolerance and dependency. These side effects, should they occur, are especially problematic for people with PD. However, early in the course of anxiety symptoms in PD, benzodiazepines can help individuals regain a sense of control, reduce anxiety, and limit worsening of avoidance behaviour.

Currently, there are other treatment options showing promise, including the use of cannabinoids and probiotics. More research needs to be conducted to truly assess their effectiveness. Although anxiety can sometimes lead to feeling overwhelmed, know that you are not alone if you are experiencing it. There are many treatment options that can be explored. Speak to your doctor about what may work best for you.

Living Well

Hiring Private Care

The decision to access additional care and support is a personal one with many considerations. As Parkinson's disease progresses, individuals may notice increasing difficulties with daily activities, such as medication management, bathing, meal preparation, and other day-to-day tasks.

If you are considering the need for additional support, there are two options to explore: publicly subsidized home and community care services, and private pay services. Utilizing these services provides the benefit of staying in one's own home and retaining independence. These services also provide much-needed respite for caregivers, allowing them to better care for themselves (*"Hiring In-home Help," n.d.*).

PUBLICLY SUBSIDIZED HOME AND COMMUNITY CARE SERVICES

Regardless of which route is chosen, it is recommended that public health services be explored first (*"The Ins and Outs of Hiring Private Care," 2017*). Individuals who meet the provincial eligibility criteria, as determined by a formal assessment, are assigned a case manager (*"Publicly Subsidized or Private Pay Services," n.d.*). The case manager then acts as a gateway for receiving services, which are subsidized through the Ministry of Health (*"Publicly Subsidized or Private Pay Services," n.d.*).

While the services available differ depending on one's health authority, the following are examples from Vancouver Coastal Health of services that may be available through the public health system (*"Costs for Home & Community Care," n.d.*):

- Home care nursing, which may include wound care, intravenous therapy, health education, and referrals to helpful community services.
- Caregiver support, which may offer respite care, as well as assistance with caregivers' personal care, recreation, and laundry.
- Occupational therapy, which may be used to increase a person's independence through work, self-care, and recreational activities. There may also be a focus on improving domestic skills, such as housekeeping, gardening, and cooking.
- Physiotherapy, which may teach and assign beneficial exercises to do at home, such as stretching or walking.
- Community nutrition, which may provide nutrition assessments, food and nutrition education, and medical nutrition therapy.
- Personal care for eligible palliative clients, which may provide basic medical care focused on symptom control, medical supplies as needed, counselling, respite care for caregivers, and bereavement services.

Although personal preferences are considered, the primary needs of individuals are identified through the formal assessment (*"Publicly Subsidized or Private Pay Services," n.d.*). Sometimes, the individual may disagree with the assessment and believe they need access to more frequent or specialized care. In this case, conflict resolution measures should be applied, such as speaking with their case manager's superior, and in more complex situations, a formal complaint can be filed with the local health authority.

OTHER PUBLICLY FUNDED PROGRAMS

Choice in Supports for Independent Living (CSIL) is a publicly funded, provincial program that provides people with significant physical limitations the funds to purchase their own home support services (*"Choice in Supports for Independent Living," n.d.*). Eligible clients are given control over many aspects of their CSIL care, including which provider to hire, as well as how to spend the funds (*"Choice in Supports for Independent Living," n.d.*).

CSIL clients receive a set amount of funding each month, calculated by multiplying a CSIL hourly rate (*which is predetermined annually*) by the number of hours of home support they need (*"Choice in Supports for Independent Living," n.d.*). Individuals typically pay a small monthly contribution amount for these services (*"Choice in Supports for Independent Living," n.d.*). However, for those receiving certain government income benefits or meeting specific criteria, the monthly contribution may be reduced or waived (*"Choice in Supports for Independent Living," n.d.*). To learn more about CSIL, please visit <https://bit.ly/CSILsupport>.

PRIVATE PAY SERVICES

Individuals may wish to hire private pay services for a wide variety of reasons, including gaps in what is offered through the public health system, or a need for more consistent and/or frequent care. The benefit of private pay services is that they are directly accessed from the service provider, and as a result, there is no need for a formal assessment (*"Publicly Subsidized or Private Pay Services," n.d.*). Individuals are also free to compare service providers to find an ideal match between their needs and the provider's offerings (*"Publicly Subsidized or Private Pay Services," n.d.*). However, such services receive no government funding and are paid for out of pocket.

When hiring private care, the choice can be made to go through an agency or directly hire an independent care provider (*"The Ins and Outs of Hiring Private Care, 2017*). Agencies are a common first choice, as they normally handle administrative matters, such as criminal background checks and employee training (*"The Ins and Outs of Hiring Private Care," 2017*). Some individuals may prefer to directly reach out to prospective independent care providers, using newspaper classifieds or online postings (*"The Ins and Outs of Hiring Private Care," 2017*).

This option may provide more flexibility and a larger talent pool, but can also be riskier and more time-consuming (*"The Ins and Outs of Hiring Private Care," 2017*).

CONSIDERATIONS FOR HIRING PRIVATE CARE

Person-centred care is an emerging care practice that places a holistic focus on an individual's emotional, as well as physical, needs and preferences (*"Person-Centred Care in Nursing Homes and Assisted Living," 2017*). Because life with Parkinson's disease is a journey of different stages and challenges, choosing a person-centred care provider will ensure individuality is respected (*"Person-Centred Care in Nursing Homes and Assisted Living," 2017*). Reading a care provider's values and mission statement, is a good place to get an idea of their approach.

After a shortlist of options is compiled, an interview process should take place to find the right fit for your particular care needs. Interview questions can cover a wide breadth of topics, including previous work experience and why they are the ideal candidate for the job, as well as situational questions, such as how they might handle a complex matter regarding confidentiality or client aggression (*"The Ins and Outs of Hiring Private Care," 2017*). These questions may include:

- How many years has this agency/individual provided services of this nature?
- What are the costs, and is travel time included?
- Does the agency/individual have any form of accreditation, usually granted by a third-party organization?
- Will they supply references to verify the quality of their work?
- If using an agency, are criminal background checks required of all employees providing direct patient care?
- If using an agency, will the same care provider render services every time, or will staff rotate frequently?
- What happens if the provider is unable to attend a scheduled visit? Is there a refund policy in place?

Once a provider has been chosen, duties and expectations should be stated clearly. For this, a service contract can be extremely helpful (*"The Ins and Outs of Hiring Private Care," 2017*). The service contract should state the responsibilities of the job, including hours to be worked, rate of pay, and obligations for termination, amongst others (*"The Ins and Outs of Hiring Private Care," 2017*). Agencies typically have contract templates available (*"The Ins and Outs of Hiring Private Care," 2017*). It is also important to ensure that appropriate insurance coverage is in place, such as WorkSafe BC and home insurance (*"The Ins and Outs of Hiring Private Care," 2017*). Additional motor vehicle coverage may also be required, depending on the nature of the care arrangement (*"The Ins and Outs of Hiring Private Care," 2017*).

If you are hiring a care provider as an independent contractor or employee, depending on the details of the working arrangement, you may need to enter into an employer-employee relationship (*"The Ins and Outs of Hiring Private Care," 2017*). If you have specific questions and concerns about the legal obligations related to hiring contractors, further information is available at <https://bit.ly/ESAFactsheet>.

Last but not least, checking references and receiving photocopies of any certificates or credentials is an important final step (*"The Ins and Outs of Hiring Private Care," 2017*). By viewing a provider's professional distinctions, along with testimonials of past success, individuals can feel assured they have chosen the right care for their needs.

ADDITIONAL RESOURCES

- **Choice in Supports for Independent Living**
Website: <https://bit.ly/CSILsupport>
- **Canadian Database of For-hire Caregivers**
Website: www.caregiverjobs.ca
- **Employee or Independent Contractor Fact Sheet**
Employment Standards BC: <https://bit.ly/ESAFactsheet>
- **WorkSafe BC | Hiring Someone to Work in Your Home**
Website: <https://bit.ly/WorkSafeBChome>

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Why expanding the Deep Brain Stimulation program in British Columbia is critical

Deep Brain Stimulation (DBS) is a potentially life-changing surgery used to correct overactive brain activity as a result of Parkinson's disease (PD). It can help treat the motor symptoms of the illness, such as tremor, rigidity, stiffness, slowed movements, and walking problems. During the procedure, a small platinum electrode or wire is placed into the abnormal area of the brain, which is then "turned off" through the use of high frequency electrical stimulation. DBS is typically reserved for people with Parkinson's who have symptoms that cannot be managed through the use of medication.

Across Canada, there is at least one functional neurosurgeon for every two million people – except in BC, where it is one for every five million. In 2019, the BC Ministry of Health announced that they would be increasing the capacity for DBS surgeries by doubling operating room time and recruiting an additional neurosurgeon. To date, Dr. Christopher Honey remains the sole neurosurgeon who performs DBS in BC, and

the waitlist for initial assessment is up to four years, followed by an additional six months to a year for a surgical date. As a result of this, people with PD in BC continue to face undue hardship and suffering.

Further adding to this issue is that DBS can only be performed during a certain window of opportunity, where a person's Parkinson's is advanced enough to need the intervention, but healthy enough to tolerate a surgical procedure. As Parkinson's is a progressive disease, a lengthy wait can result in surgery no longer being a viable option for some individuals. This devastation is a reality being faced by British Columbians and it needs to change. We can do better for people with Parkinson's.



Waiting for DBS

Angela & Mark Hutchinson

Angela and Mark Hutchinson know firsthand the frustration of waiting.

Mark serves on the Board of Directors

for Parkinson Society BC (PSBC) and is a carepartner to his wife, Angela, who was diagnosed with PD in 2008 after first noticing a tremor in her right hand. The progression of her symptoms during the first decade was relatively slow, but has accelerated in the last two to three years. The advancing symptoms of Parkinson's have had a significant impact on Angela's daily life. She experiences tremors all over her body, as well as pain, sleep difficulties, and fatigue. At times, Angela struggles to walk due to curling of her toes and leg stiffness, which makes it challenging for her to remain as physically active as she once was.

As Angela's symptoms have progressed, so have the quantities and types of medications she takes. When she first started taking medication 11 years ago, she took four pills each day. "Today, she takes 26 pills daily, spread over five doses, every three hours," says Mark. "This alone has an impact on our lives, as we are never far away from time for another dose."

In October 2019, Angela's movement disorder specialist said that he could no longer improve her quality of life with medication alone, and that he would refer her to Dr. Honey to be assessed for DBS. The couple believes that the benefits of this surgery would be far-reaching for Angela. Improved quality of sleep, as well as energy

levels, would potentially allow for more consistency and 'on' periods throughout the day. Better energy levels would also enable Angela to do more of what she loves, which is to spend time with her friends and family, exercise, play pickleball, and enjoy meals at restaurants.

Since the date of the referral, the process has been slow to move forward, and Angela remains on the waitlist to be assessed with Dr. Honey. "This is evidence of the difficulty of this process," says Mark. "It is frustrating that you could wait for four years to speak with Dr. Honey, hoping all that time for DBS, and then be told that you are not a suitable candidate for surgery. This would be devastating."

Like many others waiting for access to DBS in BC, Angela and Mark face a long haul. Mark says that the only way through it is to, "keep up hope, do all you can to support your loved one, and where possible, ask the specialist to keep advocating for you. You need to carry on as if there is no DBS – keep doing all the things you like to do together, don't wait for after DBS!"

“keep doing all the things you like to do together, don't wait for after DBS!”

Although she is much slower these days, Angela tries her best to lead a relatively normal, independent life. There are some practical things she cannot do on her own, such as taking photographs during a recent whale-watching trip, so Mark assists wherever he is able. The couple is intent on checking things off their bucket list sooner rather than later, as they are aware that Angela may not be as mobile and able in the years to come. "We focus on the here and now, and do what we can while we can."



How DBS changes lives

Richard Mayede

In 2005, Richard Mayede was diagnosed with Young Onset Parkinson's Disease, making him determined to be a source

of positivity and encouragement for others facing a similar journey. Richard joined PSBC's Board of Directors in 2016, which inspired him to begin his advocacy work to make DBS more accessible for British Columbians.

Despite the challenges of life with a chronic, degenerative condition, he spent 16 years managing PD with only medication and a strong, positive attitude. However, the daily struggles took a toll on him.

“I had lost my dreams somewhere along the way,” he says. “I didn’t realize I was giving up on my long-term goals, since I was so focused on being happy for being alive each day.” Once an avid storyteller and filmmaker, Richard found his advancing Parkinson’s prevented him from sitting still long enough to write. As his disease progressed, his symptoms fluctuated between the extremes of freezing and dyskinesia (uncontrollable movements). “I gave in to the thought that this was going to be my existence,” he says.

It was not until his twelfth year of living with PD that his neurologist felt he should consider DBS. Like many individuals, Richard was subject to a long wait – he spent three and a half years on the first waitlist for initial assessment, followed by another year on the second, before having surgery in February of 2021.

When it finally came time for surgery, Richard kept an open mind and had no expectations. The procedure itself took about seven hours, which included long periods of waiting. “During surgery, a lot of attention was given to my feet and hands, since they felt incredibly restless,” says Richard. It was this restlessness that bothered him, as well as the fact that he could not see clearly, because he could not wear his glasses due to the stereotactic frame on his head. This device provides stability and reference points for the surgeon. However, Richard’s surgeon, Dr. Honey, was a comforting, supportive force. “My neck was getting sore from the frame,” he says. “Dr. Honey kept reassuring me that everything was going perfectly, and he even massaged my neck and shoulders while waiting for a surgical room to open up.” The only fear he had was about the drilling of the holes for the frame, but the nurses reassured him that it would last just 90 seconds and be painless – both were absolutely true.

Fortunately, recovery was quick. “The surgeon’s medical team checked in on me the next morning and said it was okay for me to be discharged,” he says. Richard recalls that he felt no pain afterwards. In fact, on the second day after surgery, he was able to attend a physiotherapy appointment in person.

During surgery, the DBS device is implanted and is left turned off. Individuals then return to the DBS Clinic to have the device turned on after six weeks. Initially, there are weekly appointments to find the best settings. This process took about a month for Richard. Prior to the surgery, he struggled with freezing and dyskinesia, but afterwards, Richard was able to ride his bike to the clinic for these appointments.

“Things still get me to tear up, but not to the extreme I felt before.”

When reflecting on the benefits of DBS, Richard says, “what happened to me was quite incredible.” Aside from tremendous improvement of his motor symptoms, Richard has noticed some emotional changes as well. Prior to DBS, he would cry at anything that pulled at the heartstrings – even commercials. However, after surgery, he feels more emotionally level. “Things still get me to tear up, but not to the extreme I felt before,” he says. As his symptoms are now better controlled, Richard is able to resume his passion, which is filmmaking. He recently won a grant to produce a documentary on what people with Parkinson’s do to stay positive. He hopes to shed light on this disease and show the general public that PD is more than just tremors. “I’ll be turning 54 this year and finally, I’ll get to fulfill my dream of producing my own project,” he says. Richard credits DBS with making this a reality. “DBS has helped me see that my dreams are still possible. I feel like I have my life and hopes back.”

Although we are encouraged by the work done to increase the number of DBS surgeries since 2019, the hiring of a second neurosurgeon is yet to happen. This is a crucial step in reducing the needless suffering caused by the lengthy DBS waitlist for British Columbians. Parkinson Society BC is asking for your support in urging the BC Ministry of Health to move forward on their promise to provide more timely access to DBS. Please take action and support our campaign today by writing to your local MLA, the Minister of Health, and the Assistant Deputy Minister. To learn more and download editable letter templates, visit www.parkinson.bc.ca/DBS.

Carepartner's Corner

Tools and resources for caregivers

May is Family Caregiver Month, an opportunity to acknowledge and celebrate the dedicated efforts of caregivers across the province. Over one million caregivers in British Columbia provide 80% of the care for their loved ones, contributing \$3.5 billion in unpaid labour to our healthcare system annually (*"Caregivers in Distress: A Growing Problem," 2017*).

Life with Parkinson's disease (PD) has a profound effect, not only on the person diagnosed, but also on those close to them. While being a caregiver may strengthen relationships and foster deeper connections, its many challenges can impact day-to-day responsibilities, like self-care and employment, as well as relationships with family and friends. Care is not limited to just physical tasks, but can also include emotional and spiritual support. Assessing your individual strengths can help shape your role as a caregiver and allow you to supplement them with help from others. Taking a proactive approach means you can participate in making informed decisions and be involved in healthcare discussions. It will also allow you to implement the support you and your loved one need, while helping alleviate some of the stresses associated with caregiving.

For the purposes of this article, the term 'caregiver' will be used to encompass a broad range of relationships in which one or more individuals care for someone. We recognize that not every person providing care to a loved one identifies as a caregiver. Some may prefer the term 'carepartner,' as this term includes and recognizes those who are not usually the sole decision maker in their loved one's care, but rather assist where necessary.

HELPFUL TOOLS AND RESOURCES FOR CAREGIVERS

Because the role of a caregiver can last many months or years, it is important that it is sustainable. Despite the importance of ensuring their own needs are met, many caregivers struggle with multiple, conflicting demands on their energy and time. Fortunately, there are many tools available that can help ease the burden on caregivers and restore balance in their lives.

PARKINSON SOCIETY BC RESOURCES

Tools for Caregivers

Parkinson Society BC (PSBC) is committed to offering support and sharing reliable information, so that every person touched by Parkinson's knows they are not alone. We are proud to support caregiver wellbeing with the following resources:

- **Support Groups:** Joining a support group can be an opportunity to meet others with similar experiences in a friendly, supportive setting. These groups are a great reminder that you are not alone in your journey. To join one of Parkinson Society BC's caregiver support groups, please visit www.parkinson.bc.ca/groups.
- **PDLink:** PSBC recognizes that not every caregiver has access to a support group or is comfortable in a group setting. PDLink, a peer-to-peer support program, was developed as an alternative, or complement to, our support groups. It matches people with PD and/or their caregivers with someone that has similar experiences to their own. Once paired, participants can communicate over the phone or via e-mail – in-person interaction is not required. To learn more, please visit www.parkinson.bc.ca/pdlink.
- **Counselling:** Parkinson Society BC offers free, short-term, and non-crisis counselling services. Counselling will provide you with a safe and structured environment to discuss challenges and process emotions. Visit www.parkinson.bc.ca/counselling to learn more or book an appointment.
- **Journaling:** Writing down what's going on in our minds can help us clarify our thoughts and feelings in a safe and private way. Caregivers may find that incorporating a journaling practice into their self-care routine can help them grow self-awareness and better cope with difficult feelings. For tips on how to start journaling, please visit www.parkinson.bc.ca/covid19-journaling.

PD-Specific Tools

Tools aimed at helping a loved one with Parkinson's can alleviate stress, while providing caregivers the peace of mind that their loved one is receiving appropriate care. Here are two tools that can help:

- **Aware in Care:** With more frequent visits and a high sensitivity to the timing and dosing of medications, people with PD face greater risks in the hospital. The Aware in Care kit is designed to protect, prepare, and empower people with Parkinson's and their caregivers for a hospital visit. Each kit includes various tools and information to ensure people with PD get the best possible care during a hospital stay. To learn more or to order a kit, please visit www.parkinson.bc.ca/awareincare or phone 1-800-668-3330.
- **ParkiTrack:** Helping a loved one with Parkinson's track their symptoms does not have to be complicated. ParkiTrack was designed to help people with PD get the most out of their medication. Caregivers can help log symptoms and medication side effects, so they may be discussed at future neurologist appointments. Download a digital copy at www.parkinson.bc.ca/parkitrack.

OTHER DIGITAL RESOURCES

Smartphone Apps

Caregivers often have a lot on the go, balancing their personal obligations with the needs of their loved one. It can be overwhelming having to juggle so many commitments simultaneously. However, many of us hold a powerful key to organization and better time management right in our pockets. Smartphones provide us with access to many useful, convenient tools with just the swipe of a finger. Here is a list of free apps that can help caregivers better manage their time as they continue providing the best possible support for their loved one. Each app listed below is available for download via the Apple App Store and Google Play:

- **Lotsa Helping Hands:** This is a community-building app that enables multiple caregivers to create a network of support around their loved one. They can post tasks others can assist with, such as rides to appointments, meal and grocery deliveries, and visiting hours. Friends, family, and neighbours can volunteer to help whenever they are able, which can help alleviate some of the responsibilities of the primary caregiver. The app also allows caregivers to post updates for anyone in their loved one's support system, along with uplifting and loving messages.
- **Medisafe Pill Reminder:** This app helps with medication management by providing timely alerts. If an individual with PD forgets to take their medication on time, a caregiver receives a notification on their smartphone, advising them to check in on their loved one. Additionally, the app provides a series of helpful reminders, such as appropriate times for a prescription refill pickup or a new doctor's appointment.
- **Google Calendar:** This digital calendar app provides an easy-to-use scheduling assistant that can help caregivers stay organized. It can schedule events directly from Gmail while integrating seamlessly with all the calendars on a device, including Microsoft Exchange and iCloud. Use it to track medical appointments and caregiving commitments, as well as to carve out blocks of self-care time.
- **First Aid - Canadian Red Cross:** This app provides step-by-step instructions and videos for common first aid scenarios, arming caregivers with vital, potentially life-saving information. Content is preloaded and saved to the device locally, so no internet connection is required to access the app in case of an emergency.

Virtual Mental Health Tools

Unfortunately, COVID-19 has compounded the challenges presented to caregivers, as they have had to navigate the pandemic while continuing to care for their loved one. Over 50% of caregivers reported a decrease in their mental health during the pandemic, and half stated they were providing up to 10 hours of extra care per week (*"Family & Friend Caregivers on the Front Lines," 2021*). During these unprecedented times, it is more important than ever for caregivers to prioritize their mental wellbeing. Here are some free, accessible digital options that may help:

- **Elizzbot:** This on-demand, confidential smart chatbot was designed with family caregivers in mind. Elizzbot utilizes self-learning artificial intelligence to help caregivers build resilience and self-awareness using cognitive behavioural therapy (CBT) skills. It can be contacted via Facebook Messenger, or text message by texting "Hi" to 647-492-8640. Learn more at www.elizz.com/elizzbot.
- **Bounce Back® BC:** This virtual mental health skill-building program is based on the principles of CBT and is available to British Columbians who are suffering from mild to moderate anxiety or depression. Individuals can choose to work alone or with a Bounce Back® trained coach, who will help them work through the material in up to six telephone sessions over three to six months. Learn more at www.bouncebackbc.ca.
- **7 Cups:** This anonymous 24/7 chat is staffed by trained volunteer listeners who are ready to lend a compassionate ear whenever one is needed. Caregivers may find that having someone who nonjudgmentally listens makes a world of difference. Discover more at www.7cups.com.

As every individual with Parkinson's disease is on their own unique journey, there is no one-size-fits-all approach to caregiving. However, what is certain is that caring for a person with Parkinson's means caring for yourself. When caregivers are able to manage their time, fulfill their obligations, and lead satisfying, happy lives, they are then able to provide the best support for their loved one with PD.

Disclaimer: Please note that many of the apps, products, and services mentioned in this article are operated and offered by third-parties. The mention of these services is not to be considered an endorsement by Parkinson Society BC, but rather to provide options for your consideration.

ADDITIONAL RESOURCES

- **A Comprehensive Guide for Parkinson's Caregivers**
Booklet: <http://bit.ly/pdcaregiverguide>
- **Caregiving in a Family with Parkinson's**
Helpsheet: <http://bit.ly/pdffamilycare>
- **Time Out for Carepartners Series**
Videos: <https://bit.ly/timeoutforcarepartners>

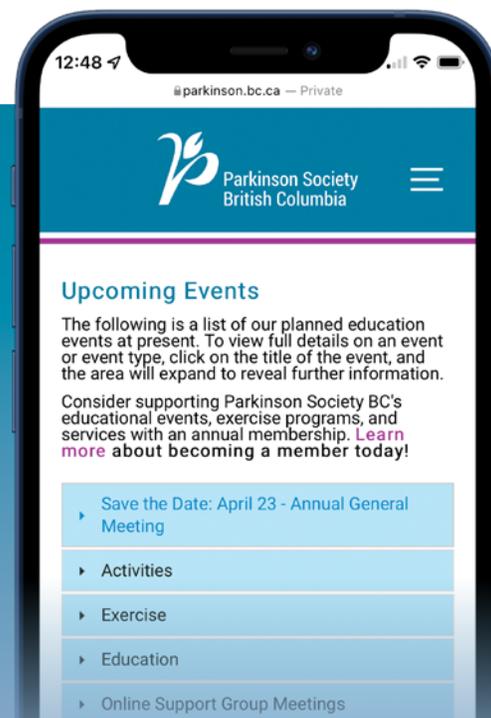
SOURCES

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- Family & friend caregivers on the front lines (n.d.). Family Caregivers of British Columbia. Retrieved from: <https://www.familycaregiversbc.ca/wp-content/uploads/2021/04/210322-FCBC-COVID-19-Survey-Highlights-Release-rev2b-1.pdf>

Online Calendar

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

parkinson.bc.ca/events



Newsorthy

Upcoming Education & Exercise Events

Bollywood Dance

Tuesdays, April 5 – 26: Gina Fernandez, Occupational Therapist & certified PWR! Moves Therapist

April Challenger

Thursdays, April 7 – 28: Shelly Yu, Physiotherapist and PD Warrior certified

2021 Annual General Meeting

April 23: Online via Zoom

Carepartner Series

May (to be determined): Speakers to be determined

Balance Exercise Series

Tuesdays, May 3 – 31: Shelly Yu, Physiotherapist and PD Warrior certified

Virtual Open House

May 10: Liz Janze, Education & Support Services Coordinator at PSBC

Hand & Dexterity Exercise Class

June (to be determined): Shelly Yu, Physiotherapist and PD Warrior certified

GLOBAL SYMPOSIUM SERIES

- **Breakthrough Therapies for Parkinson's**
May 4: Dr. Michael Okun, Movement Disorder Specialist, is recognized as one of the world's leading researchers of Parkinson's. Join us in this webinar, where Dr. Okun will discuss breakthrough therapies for Parkinson's. Developments in the understanding and treatment of PD over the years will also be explored.
- **Gyro-Kinetics for Parkinson's**
May 11: Alex Kerten joins us to discuss Gyro-kinetics, a breakthrough method he developed that helps manage and decrease PD symptoms. He will also discuss his book, *Goodbye Parkinson's, Hello Life*, which describes how Gyro-kinetics can help people with PD live productive and fulfilling lives.

• Personality and Behaviour Changes

May 20: Dr. Antonio Strafella, Neurologist, will discuss personality and behaviour changes that can develop for individuals with PD, such as apathy, irritability, and emotional bluntness. Impulse control problems, like hypersexuality and compulsive gambling and/or eating, will also be explored.

REGIONAL CONFERENCE

June 18: Ramada Hotel & Conference Centre, Kelowna, BC

- **Managing Postural Hypotension:** Dr. Melissa Mackenzie, Movement Disorder Specialist
- **Bladder and Bowel Issues:** Dr. Jenn Locke, Urologist
- **Diet and Nutrition:** Dr. Sally Stewart, Associate Professor of Teaching in Health and Exercise Sciences

Save the Date

Moving Forward, Together returns this fall on **Saturday, October 15!**

Thank you to our fundraisers and donors!

DONATE A CAR

In 2021, the Donate a Car program raised \$710. Thank you to all those that chose to donate their car in support of Parkinson Society BC!

HOLIDAY CARD SALES

Thank you so much to everyone who supported our holiday greeting card campaign, featuring the work of inspirational artists living with Parkinson's across the province. Your generosity helped raise \$2,900!

A tremendous thank you to the artists whose work was featured on the cards: Garry Toop (Kelowna), Ken Meisner (Nanaimo), Marie Germain (Grand Forks), and Susanne Touhey (Kamloops), as well as to all those who submitted their artwork.



APRIL IS PARKINSON'S AWARENESS MONTH

Every year, Parkinson Society British Columbia (PSBC) dedicates the month of April to raising awareness of the unique experiences of people with Parkinson's disease (PD). Parkinson's Awareness Month is an opportunity to engage the public in expanding their understanding of Parkinson's, and the profound effects it has on the lives of over 15,000 British Columbians living with the disease. It is also a time to draw attention to the needs of our growing community, while celebrating our successes – both big and small.

Get involved

This April, we invite you to take part in our awareness campaign to help spread the message that Parkinson's is **more than a tremor**. Get involved through:

PARKINSON'S AWARENESS MONTH POSTCARDS:

We are asking people to fill out postcards, reflecting on their personal experience with Parkinson's, in an effort to educate the public. These postcards may also be used in future communications to raise awareness. Submit your responses at <https://bit.ly/pdpostcardsubmission>, or visit <https://bit.ly/pdpostcardrequest> to request printed copies.

THE FACES OF PD CAMPAIGN:

We will be collecting photos from people with Parkinson's disease in BC to help draw attention to the diversity of the community. To learn more or to submit your photo, please visit www.parkinson.bc.ca/facesofpd.

UPCOMING SOCIAL MEDIA AND PROMOTION:

Throughout the month of April, we will be sharing facts about Parkinson's disease, as well as wellness tips, on our social media channels. Stay tuned to also see our video campaign, featuring personal journeys shared by people with Parkinson's, their families, and carepartners.

To learn more about Parkinson's
Awareness Month activities, please visit:

parkinson.bc.ca/awareness



David P.

Diagnosed with Parkinson's in 2018, at the age of 54. Loves spending time with friends and family, and is grateful to have the support of his husband, Dan.



Ryan O.

Diagnosed with PD at the age of 43. Husband and father of two. 4th degree Taekwondo black belt, as well as an undying optimist.

These photos were submitted as a part of the Faces of Parkinson's Disease campaign. To learn more and participate, please visit www.parkinson.bc.ca/facesofpd.



Wayne & Elaine B.

Married for 57 years, with two children and six grandchildren. Both diagnosed with Parkinson's just two years apart.



Yehudi A.

Semi-retired exercise enthusiast. Loves to work out at Delbrook Recreation Centre three times a week, as well as walk on the seawall.

Register Now

2021 Annual General Meeting

We welcome all members of Parkinson Society British Columbia (PSBC) to join us for our 2021 Annual General Meeting (AGM) this spring. Following the meeting, Dr. Lara Boyd will be joining us for a special presentation on the applications of neuroplasticity in managing Parkinson's symptoms.

This year's AGM will be hosted online via Zoom. Stay tuned to our website at www.parkinson.bc.ca for more details.

Register today at www.parkinson.bc.ca/agm21
Free for members. Non-members interested in attending must sign up to be a member of PSBC, and pay the \$25 annual membership fee.

Date:

**Saturday,
April 23, 2022**

Time:

**9:30am to
11:30am PT**

Location:

Online via Zoom

 **Parkinson Society
British Columbia**
600–890 West Pender Street,
Vancouver, BC V6C 1J9



RETURN POSTAGE GUARANTEED
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