

parkinson SOCIETY
SOUTHWESTERN
ONTARIO

THE PARKINSON'S UPDATE

WINTER/SPRING 2022
ISSUE 75



**Navigating
Difficult
Conversations**

Page 10

**Dance Training
for Parkinson's**

Page 12

**Deep Brain
Stimulation**

Page 14

MISSION STATEMENT

Parkinson Society Southwestern Ontario enhances the quality of life and care for people living with Parkinson's in Southwestern Ontario.

BOARD

Brad Richards (Chair)
Alysia Christiaen (Vice-Chair)
Joseph Salamon (Treasurer)
Anthony Bender
Cam Crosbie
Chris Curry
Dr. Jeff Holmes
Matthew Mitchell
Gary Pullam
Janis Shkilnyk
Dr. Mandar Jog (Honorary)

STAFF

Shelley Rivard
CEO

Joanne Bernard
Manager of Administration

Jessica Halls (on parental leave)
Manager, Fund Development

Mandy McDonagh
Programs and Services Coordinator

Dylan Murphy
Special Events Coordinator

Justine Travnicek
Data Specialist

Mark Womack
Community Development
Coordinator

Front Cover Photo:
Photo by Amber Star Merckens, courtesy
Mark Morris Dance Group/Dance for PD.

FROM THE CEO's DESK



Shelley Rivard

How quickly 2022 is moving. We are already into February. The year began just like the last several have with COVID-19 forcing us to hunker down once again, but I do feel that 2022 has many great things in store for us.

We had a great 2021 thanks to you. We were once again able to host our Parkinson Golf Classic and our **Walk for Parkinson's**, which provide much needed funds for the continuation of services and our commitment to research each year. We welcomed the Guelph Parkinson's Support Group as part of Parkinson Society Southwestern Ontario. We signed a Co-operation Agreement with Parkinson Canada. We look forward to finding ways to work more collaboratively, especially in the areas of advocacy and research.

We are happy to introduce a couple of projects this year. In partnership with Dance London, we are excited to begin Dancing with Parkinson's (see page 12) as a pilot project in London. There are many benefits of dance, including physical and cognitive exercise, balance, rhythmic motor co-ordination, memory, social interactions, and it's fun! In the fall, we hope to begin a Drumming Circle as a pilot project in Grey-Bruce. Watch for more details in the next issue of *The Parkinson's Update*.

Parkinson Society Southwestern Ontario is looking forward to a gradual return to in-person programming. We know how hard it has been to not be face to face with people or to receive a much needed hug! Through *The Parkinson's E-News Update*, we will keep you apprised of what is opening up, and when. To sign up for bi-weekly email communication, go to <https://psso.ca/stay-informed/>.

For 2022, our conference planning is underway. The Spring Regional Parkinson's Conference will take place in Walkerton on Saturday, May 7 and the Fall Regional Parkinson's Conference in Kitchener/Waterloo on Saturday, October 22. Mark your calendars. You do not want to miss these incredible events!

We anticipate Graduate Student Scholarship applications, which are due shortly. We are pleased to review all applications and to fund 2-3 projects in areas relevant to the treatment of motor and/or non-motor symptoms. Information on the successful applicants and their projects will be shared in April.

We are thrilled to plan a return to in-person walks September 10 and 11, and with that, all of the fun and engaging activities you have come to enjoy from previous years. Come for the walk, but stay for the fun, music, refreshments, and of course social interactions that we have undoubtedly missed. Unable to walk in person? No problem – join the online virtual walk and walk your own way! We look forward to seeing all of you this September!

Wherever HOME is for you, I look forward to seeing you at a conference, support group or **Walk for Parkinson's**. You are never far from HOME with Parkinson Society Southwestern Ontario.

Shelley Rivard

Shelley Rivard
CEO

HOPE IS CLOSE TO HOME

You are Never Far from Home with Parkinson Society Southwestern Ontario

HOME FOR EDUCATION

- Spring and Fall Parkinson's Regional Conferences (*both in-person and virtual*)
- The Parkinson's Update newsmagazine (*semi-annually*)
- The Parkinson's Enews Update (*bi-weekly*)
- Resources in print and online at psso.ca
- Educational workshops and webinars
- Parkinson Education Program (PEP) for Community Caregivers online training program for healthcare professionals at peponline.ca

HOME FOR SUPPORT

- Toll-free information and referral line, 1-888-851-7376
- Counselling in partnership with King's Western University Social Work program
- Access to Support groups and exercise programs
- The Newly Diagnosed series
- Weekly Coffee Klatch (an informal virtual social group)
- Parkinson's Music Choir
- Louder, Clearer: A Parkinson's Voice Training Program
- Access to local community experts
- Information packages

HOME FOR RESEARCH

- Graduate Student Research Program
- Clinical Movement Disorder Fellowship Program
- The London Movement Disorders Centre Brain Bank

HOME FOR ADVOCACY

- Ensuring the voices of people living with Parkinson's are heard on issues important to their well-being through the PSSO Advocacy Committee
- Guidance and support for the implementation of local initiatives



Regional Office:

123-4096 Meadowbrook Dr, London, ON N6L 1G4

Phone (519) 652-9437

Toll Free..... 1-888-851-7376

Fax (519) 652-9267

✉ info@psso.ca

🌐 www.pssso.ca

📘 [ParkinsonSocietySWO](https://www.parkinsonsociety.swo.ca/)

📺 [parkinsonswo](https://www.parkinsonswo.ca/)

Although we make every effort to ensure that the information in The Parkinson's Update is accurate, we cannot take responsibility for any errors or omissions. Information is sometimes taken from letters to the editor, submissions from the Internet or other print material. We make an effort to acknowledge all of our sources.

The information is not intended to take the place of professional medical advice. If you are a patient currently being treated and have questions, or if you think you have Parkinson's but have not been diagnosed, please seek the advice of a medical professional. This information does not replace consultation with your physician.

I Have Parkinson's But It Doesn't Have Me: Bill Robson

In his late 40s, Bill began having random choking episodes. He would be eating or drinking at home or in a restaurant. His throat would simply close up and panic would set in. With the advice and support of his doctor, he learned breathing techniques to control the fear and to allow airflow. Little did he know, he was about to embark on a 20-year journey to a Parkinson's Disease (PD) diagnosis.

Over time, other symptoms began to occur – memory loss, moving a bit slower than usual, fatigue – all put down to normal aging. But then the tremors began. Food wouldn't always stay on his fork and when he moved, he had a sensation of falling while remaining upright. At that time, in his 60s, after doctors, neurologists and the Toronto General Hospital Movement Disorder Clinic, he received his diagnosis. It was real.

After the initial shock and disbelief subsided, Bill wondered, now what? "It's like a fork in the road where you choose to let it get you or you walk along the path that looks harder but allows you to keep living your life the way you want to and not give PD power or control. It's my choice to keep that control."

Now a few years later, the symptoms are stronger and more apparent. Words don't always come out as planned and he is often unsteady. Once an avid guitarist, his fingers don't move well enough for him to play any longer. An active volunteer with hospice providing grief support and transportation for others, and a grief facilitator with Bereaved Families of Ontario, he's had to make a few changes in the type of volunteer work he does with these organizations. Driving is awkward at times, and there are days where his concentration isn't where he wants it to be.

While navigating through Parkinson's, Bill has discovered what he calls the World of PD. "Parkinson's is truly a global issue and I have had the opportunity to be involved in online peer support groups, sharing my experience and learning from others about medications, available supports, and how friends and family react. These platforms create an awareness of the devastation of Parkinson's, but also celebrate the miracle of how everyone uniquely adapts and moves on. The internet has been a god-send during this time."

Not one to give up his love of music completely, Bill has become a member of the Parkinson's Music Choir (<https://psso.ca/programs-services/parkinsons-music-choir/>), a therapeutic singing program to help support speech, communication and respiratory strengthening and endurance. Currently on a virtual platform, people enjoy connecting by singing and sharing songs while learning to develop stronger vocal control. A recent highlight for this group was a combined live and virtual performance at last year's Regional Parkinson's Conference.



"Parkinson's is truly a global issue and I have had the opportunity to be involved in online peer support groups, sharing my experience and learning from others about medications, available supports and how friends and family react. "

— Bill Robson

For a list of Parkinson's support groups, go to psso.ca.

Bill also participates in the Louder, Clearer program (<https://pssso.ca/programs-services/louder-clearer-a-parkinsons-voice-training-program/>), which is provided free of cost through Parkinson Society Southwestern Ontario. Louder, Clearer is an eight-week program that offers exercises and techniques to help improve vocal loudness and clarity when speaking. It also offers human connection during a challenging time.

Bill is grateful for the unconditional love and support of his wife of 42 years, Diane, as well as his four adult children, his eight grandchildren and his two great-grandchildren. One of his proudest moments over the past couple of years was when two of their older grandchildren asked him to officiate at their weddings. "I was honoured to stand and join them in matrimony. Each went on to bless us with a great-grandson, so now we enjoy even more FaceTime on our family portal".

Originally uncertain how to share his life with Parkinson's with friends and neighbours, but knowing they would see the changes, he took his chances. He was greeted with the most positive and compassionate support and acceptance. He realized Parkinson's did not define who he was, nor did it have to change him or his relationships.

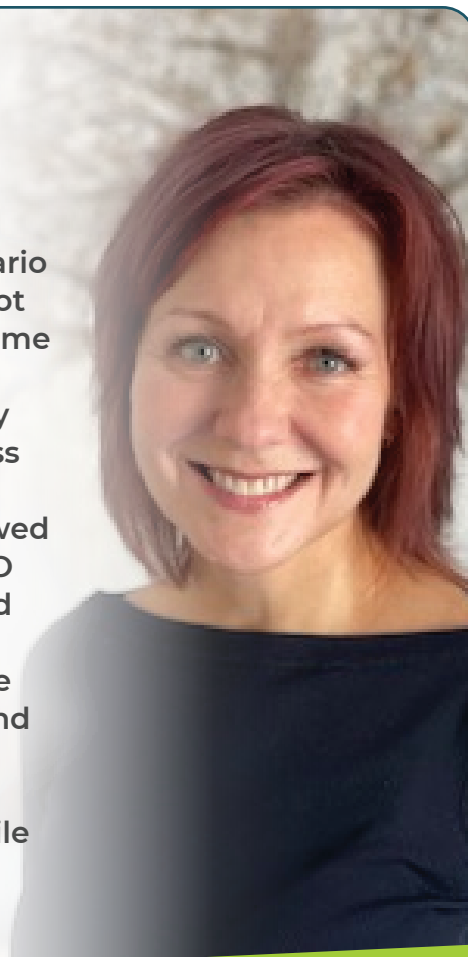
Bill offers this advice to anyone recently diagnosed or living with Parkinson's: "PD is not a death sentence! It is a call to evaluate your life, how you spend your time. Little by little PD will redefine your abilities, but it does not have to define who you are as a person on the inside. Be the best you can be at whatever you decide to do or to be. My favourite phrase is now made up of 10 powerful two-letter words – "IF IT IS TO BE, IT IS UP TO ME." Words to live by.



Written by Cheryl Losch,
Volunteer, London

“

I have been volunteering with Parkinson Society Southwestern Ontario for over 10 years. Not only has this given me the opportunity to join the community in raising awareness about Parkinson's, but it has also allowed me to join the PSSO family of caring and dedicated people. Working with these amazing people (and having lots of fun!) while contributing to such a worthwhile cause has truly enriched my life.”



BECOME PART OF OUR TEAM
**VOLUNTEER
TODAY!**

Volunteering encompasses acts of kindness (no matter how big or small) AND the magic that happens when we work together towards a common purpose.

To find out how you can become part of our volunteer team, go to **pssso.ca**.

VOLUNTEERS URGENTLY NEEDED

Walk for Parkinson's and support groups.
Contact us at **info@pssso.ca**.

ASK THE EXPERT

Dr. Mandar Jog trained in Neurology and Movement Disorders at the University of Toronto and completed a post-doctoral fellowship in Computational Neuroscience at the Massachusetts Institute of Technology in Boston. Currently, Dr. Jog is a Professor of Clinical Neurological Sciences at Western University. He is the Director of the Movement Disorders Program at London Health Sciences Centre. The Clinic has received the prestigious designation of 'Centre of Excellence' awarded by the National Parkinson Foundation, Inc.



What is the easiest way to get a referral to your office? How long will it normally take to set up an appointment, and who will I see?

The easiest and only way to get into the Movement Disorder Centre to be seen is to get a referral from a family physician. It is important that documents on completed treatment be in the referral, as well as many documents as possible from other neurologists about what has been done in terms of therapeutics for the patient's condition. The normal wait times vary between 12-18 months. However, if there is a true medical urgency, then the physician referring can contact our office and we can place the patient on our cancellation list.

Because we are a teaching centre, we have a large assortment of fellows. I want to assure everyone that fellows are fully trained and certified neurologists. Many of our fellows come from all over the world. It is critical to understand that they are all certified as neurologists in their country and that training has been accredited by the College of Physicians and Surgeons of Ontario (CPSO) and by myself regarding their quality as performing neurologists. However, they are learning the science and art of movement disorders including Parkinson's disease and treatment, and all cases are reviewed by senior consultants in the Movement Disorder Centre. It is also possible that we have residents who are not yet certified neurologists going through our service. These residents are not yet allowed to practise independently, but they are still well-trained through our residency program. All patients are reviewed by a consultant and management decisions are made together.

I know that changes in medication dosages vary patient to patient, but on average, how long should it take for me to notice a difference once my medication has been increased – a day, a week, a month?

This is a good question. When we initiate Levodopa treatment, it is done slowly to avoid side effects such as nausea. Therefore, it can take many weeks to titrate the dose up to a therapeutic level. In other words, I usually bring patients back after six months, but I have them call us in about three months to see how the titration up has happened.

When it comes to increasing the medication that is different, titration schedule can be faster, or only a couple doses will increase. You should expect with Levodopa, an improvement of symptoms with even a single dose because Levodopa is dosed like that. However, other slower acting drugs such as dopamine agonists can take several weeks to titrate up and an improvement might take several more weeks. It is reasonable to consider with Levodopa, a week or two might be required as the physician might be titrating every dose but slowly. However, to expect an overall global improvement might take a couple of weeks, not several months, with simply an increase being done.

How can I recognise, prepare and deal with my "on" and "off" periods?

The recognition of "on" and "off" periods is specific to the individual. Most of the time, the "on" and "off" states are determined by the motor syndrome worsening or improving. This includes symptoms such as tremor, stiffness, slowness, shuffling, low volume of voice, etc. However, there are many other symptoms that are also involved in "off" periods which would be non-motor such as anxiety, mood, pain, etc. Therefore, Levodopa, which can treat many motor and non-motor symptoms, can be adjusted and the symptoms can be made to improve both these categories. It is important for you to identify those symptoms for which the original therapy was initiated and the adjustments that have been made to the Parkinson's disease medications. It is these symptoms you would notice in the fluctuation of "wearing off". As mentioned before, this could be motor or non-motor or both.

In order to deal with these symptoms, one has to determine the severity of these off periods. "Wearing off" of medications is quite common, but it doesn't mean it produces a disability. In order to have medication adjustments done by your doctor, it is important to determine if these "off" periods are producing a functional impairment. If this is the case, there may be many strategies that can be employed. They may not even be adjustment of typical Parkinson's disease medications, but there could be other ways of dealing with these "off" periods.

Is there anything I can do to help normalize my blood pressure?

This is a difficult question. There is no such thing as normalizing blood pressure when there are many medications that have an impact on blood pressure. I will divide this into two categories.

1. Hypertension, which is high blood pressure. Patients with Parkinson's disease should not have hypertension related to the disease or medications used for treatment of Parkinson's disease. Therefore, if you have high blood pressure, despite the medications that we are giving you for Parkinson's disease, that needs to be treated separately and you need to speak with your family doctor about hypertension.
2. Most of the time patients with Parkinson's disease have low blood pressure. First of all, consumption of dopaminergic medications is itself a culprit. The drugs used, including Levodopa, dopamine agonists and Amantadine, will lower blood pressure. The physician should be made aware of the fact this is occurring, with symptoms such as dizziness and light headedness when standing. It is also common that patients with Parkinson's disease have less fluid consumption and low blood pressure can be a result of this. For treatment of lower blood pressure, increasing water content throughout the day and taking a full glass of water with every dose of Levodopa could be an easy way. Stockings and even abdominal binders can be used if the blood pressure is too low. Finally, if the blood pressure is still low, despite adjustment of fluid consumption, then oral medications to increase blood pressure can be prescribed. This is parallel to adjusting medications that are being used for Parkinson's disease treatment.

I have heard that skin cancer is more common in people with Parkinson's disease. Is this true? If so, why?

Indeed, melanoma is more common in patients with Parkinson's disease, but this is still a difficult question to answer. Brain cells are also skin cells, called ectoderm. Therefore, there may be some linkage to this embryological notion to pigmented cells in the substantia nigra and melanized cells in the skin, which is not the same melanin in the brain as in the skin. The short answer is that we don't know. There is some evidence that exposure to Parkinson's disease medications may increase skin cancer, but this is not a reliable set of data. There is no restriction placed on using our drugs for treatment of Parkinson's disease with a potential risk of skin cancer.

*If you have a question for **Ask the Expert**, please email info@psso.ca. Although all questions will be considered, we cannot guarantee that your question will be published.*

BECOME A HERO OF HOPE

Our Membership Program

By becoming a member, you join as a Hero of Hope. Your monthly gift makes hope possible. You not only provide sustainability for services and Parkinson's programs including research, but you also invest in the lives of people with Parkinson's in our community.

Simply fill out the form on our website psso.ca/how-to-help/hero-of-hope/ or call **1-888-851-7376**.

Exercises for Parkinson's

Rock Steady Boxing and PD SAFEx™ Exercises for Parkinson's

As a current Ph.D. student at the University of Waterloo, I have had the pleasure of focusing my research on exercise strategies for people living with Parkinson's. I began my research venture under the supervision of Dr. Almeida, as an undergraduate thesis student with a focus on health policy perspective to evaluate the delivery of boxing programs for PD in Canada. Then I continued into my M.Sc., aiming to investigate whether the progression of Parkinson's could be influenced with exercise rehabilitation. I compare boxing programs to sensory exercise, in the first randomized control trial of its kind to compare two exercise programs with the exact same length and washout (no exercise) periods. The two exercise programs I compared were boxing (Rock Steady Boxing) and sensory exercise (PD SAFEx™).



This exciting work was published in the top clinical journal Sangarapillai, K., Norman, B. M., & Almeida, Q. J. (2021). Boxing vs Sensory Exercise for Parkinson's Disease: A Double-Blinded Randomized Controlled Trial. *Neurorehabilitation and neural repair*, 35(9), 769–777. <https://doi.org/10.1177/15459683211023197>.

The results of this study showed that in comparison to boxing exercise, sensory exercise was able to improve the motor symptoms of Parkinson's. Even more interesting, the effects of sensory exercise did not disappear even after ten weeks of no exercise. However, people in the boxing exercise group reported improved quality of life, which was sustained throughout the duration of the study and even at the end of the exercise treatment (after washout). This means that PD SAFEx™ may be able to modify progression. Thus the study highlights the importance of not only improving motor symptoms but quality of life as well.

While I was completing my master's project, I found myself running into another problem. Because of COVID-19, research everywhere came to a halt. It became impossible to complete in-person assessments after the exercise programs were completed. This made me realize that COVID-19 was not only a barrier for in-person assessments, but for geographical distance as well. We quickly realized that living in remote or rural areas might prevent people living with PD from participating in research, or even have an accurate assessment of their symptom progression. In response to this, I created an equation now commonly referred to as the "Almeida-Sang equation", which has been published in a high-ranking Parkinson's journal. Sangarapillai, K., Norman, B. M., & Almeida, Q. J. (2021). An equation to calculate Unified Parkinson's Disease Rating Scale (UPDRS) motor severity for online and rural assessments of Parkinson's. *Parkinsonism and related disorders*, 94, 96-98. Advance online publication [https://www.prd-journal.com/article/S1353-8020\(21\)00435-1/fulltext](https://www.prd-journal.com/article/S1353-8020(21)00435-1/fulltext).

With this equation, researchers and clinicians will be able to calculate the severity of symptoms using online assessments, even without some of the tests that can only be done in person.

My master's project helped to answer important questions pertaining to the effect of exercise on disease progression in Parkinson's. In addition, my master's work led to the creation of an equation that can be used for online assessments of symptoms during COVID-19 and beyond in rural communities where specialists may not be accessible.

After the completion of my master's, I was delighted to find out that my Ph.D. research would be supported by Parkinson Society Southwestern Ontario graduate student scholarship. With this scholarship, I hope to understand what causes walking difficulties in Parkinson's. Then I hope to treat these impairments using targeted exercise strategies. Through my work I hope I'm able to offer some solutions to the challenges faced by people living with Parkinson's disease and

improve their quality of life.



Kishoree Sangarapillai's Master's Thesis on Rock Steady

Boxing and PD SAFEx™ Exercises for Parkinson's was published in the Top Clinical Rehabilitation Journal. Kishoree is a Graduate Student Research Program grant recipient through Parkinson Society Southwestern Ontario.

American National Institute of Health (NIH) Makes Largest Investment in History to Slow Parkinson's Progression – And the Largest Site is in Ontario!

More and more, exercise is becoming recognized as a critical part of the "prescription for Parkinson's", but a critical question is the intensity of this prescription. Is high-intensity or moderate-intensity exercise more effective in slowing the progression of the disease?

Researchers at Wilfrid Laurier University are collaborating on a new Phase III, multi-site clinical research trial to test if high-intensity exercise is more effective in decreasing the signs of Parkinson's disease in individuals who have not initiated medication for Parkinson's. This is the first time high-intensity endurance exercise is being studied across a large number of sites in both the U.S. and Canada, and in a diverse population.

The trial, called SPARX3, will be led by researchers at Northwestern University in Evanston, Illinois. Laurier's MDRC is one of 28 research sites across North America. Only two of these sites are in Canada, and the largest recruiting site of all 28 sites is Laurier's Movement Disorders Research and Rehabilitation Consortium (MDRC). They will be recruiting de novo (unmedicated) Parkinson's clients, aged 40 to 80, to be randomly assigned to either moderate-intensity or high-intensity exercise training. They will exercise for 18 months, four times a week for 30 minutes under close supervision, and then be followed up for another six months.

"We are delighted that Laurier is the largest recruitment site, responsible for nearly 20 per cent of all recruitment in this multi-site trial," says Dr. Quincy Almeida, director of the MDRC. "We are thrilled that exercise is being recognized as an important therapy for Parkinson's disease. Unique to this study is new brain imaging technology to diagnose and document progression with the use of DaT scans, a form of imaging dopamine function."

The signs and symptoms of Parkinson's disease include progressive loss of muscle control, trembling, stiffness, slowness and impaired balance. As the disease progresses, it may become difficult to walk, talk and complete simple tasks.

The SPARX3 trial will investigate whether endurance exercise: influences the loss of signals from the brain cells that degenerate in Parkinson's disease; increases brain-derived neurotrophic factors, which are a family of proteins that induce the survival, development and function of neurons and are important for neuronal health; and reduces inflammation, which is known to be elevated in Parkinson's disease.

The research team will also collect genetic information on the participants in order to determine potential reasons some people respond better to exercise than others.



Dr. Quincy Almeida is a professor in the Department of Kinesiology and Physical Education at Wilfrid Laurier University and the Director of the Movement Disorders Research and Rehabilitation Consortium..

Practical Considerations for Navigating Difficult Conversations

It is widely acknowledged that family members, commonly referred to as informal carepartners, play a vital role in the care of people living with Parkinson's disease. They provide social, physical and psychological support over an extended period of time. Although for some individuals, caring for a loved one can be a rewarding experience, providing ongoing care often places carepartners at an increased risk for depression, stress, strain and exhaustion. The effects of carepartner stress can be seen through reductions in wellbeing for both the carepartner and the individual receiving care.

Navigating difficult conversations, those which involve strong differences of opinion or intense emotions, is known to place extreme stress/burden on the carepartner as they attempt to advocate for themselves, while simultaneously striving to emotionally protect their loved one. These conversations may include the need to discuss a delicate topic (e.g., use of overnight briefs to manage incontinence) or a significant life change (e.g., downsize family home or discontinuation of driving). Because these conversations can create discomfort, it is natural to want to avoid them. However, failing to address concerns only allows the problem to continue and potentially get worse, thus causing additional strain on the relationship.

Below are some practical considerations that can be used to help successfully manage difficult conversations.

- To ensure both parties feel prepared for the conversation, it is helpful to first bring up the topic and suggest it as something that needs to be discussed. Next, collaboratively set a date/time when both parties feel comfortable/prepared.¹
- If feelings about the topic are especially strong, to the point that it's impossible to initiate the conversation calmly, it may be helpful to first step away and engage in something that can bring you a sense of peace before attempting to start the conversation.
- It is best to conduct difficult conversations in person.² Select a location that is comfortable in temperature, quiet, private, light, with minimal distractions/interruptions.²⁻⁴
- Immediately prior to starting the conversation, make sure any basic needs are addressed (e.g., hunger, thirst, washroom, medications).⁴
- Aim to discuss challenging issues as soon as they arise, rather than allowing feelings to fester before unloading them on your partner all at once.⁵ While there may be multiple issues that warrant discussion, select only the single most important concern to address and keep to the topic at hand.³
- Begin each conversation as much as possible at the same eye level (sitting or standing).⁵ Describe your concerns and the things you'd like to happen differently. Be as clear as possible and use specific examples. Avoid the words "always", "never", "everything" and "nothing". These overgeneralize and are often inaccurate.⁵
- Approach the conversation with openness and with intent to solve the problem, rather than needing to be "right."⁵
- Difficult conversations must be reciprocal with the thoughts and feelings of both partners being valued. Make sure to provide adequate time for your partner to think, feel and respond.
- Show interest by active listening, using validating statements, expressing understanding and inviting further dialogue by asking probing questions for clarification when needed.

- To practise active listening, face your partner, make eye contact, listen without interrupting and offer nonverbal signs to show that full attention is being given to the discussion at hand.^{2,4}
- Validating statements can help the partner to feel heard.³ Examples include:
 - “I can understand how you felt that way.”
 - “You were perfectly correct to think that way.”
 - “It appears that you've thought things through very well.”
- It is important to pay close attention to your partner's emotions. If anger, frustration, sadness or fear present themselves, these should be acknowledged and worked through before moving on. This might involve showing physical presence by moving closer, offering a tissue, or giving a gentle touch on the arm.² Words to express empathy can also be helpful when delivered authentically.³ Examples include:
 - “I can see how upsetting this is to you.”
 - “I know this is not good news for you.”
 - “This is very difficult for me also.”
 - “I was also hoping for a different outcome.”
- Probing questions can deepen the conversation and help you to more clearly understand your partners point of view.³ Examples include:
 - “Tell me more about it.”
 - “Could you explain what you mean?”
 - “Could you tell me what you're worried about?”
 - “Now, you said you were concerned about (BLANK). Tell me more.”
- Once both partners have been heard, the person who initiated the conversation should summarize the discussion.^{4,6} Before concluding the conversation, work with the partner on a plan that is mutually beneficial.^{2,3}

References:

1. McQuellon, R., & Cowan, M. (2010). *The art of conversation through serious illness: lessons for caregivers*. [Ebook Central version].
2. Girgis, A., & Sanson-Fisher, R. (1998). *Breaking Bad News 1: Current Best Advice for Clinicians*. *Behavioral Medicine*, 24(2), 53–59.
3. Baile, W., Buckman, R., Lenzi, R., Glober, G., Beale, E., & Kudelka, A. (2000). SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer. *Oncologist*, 5(4), 302–311.
4. Macdonald, E. (2004). *Difficult conversations in medicine / edited by Elisabeth MacDonald*. [Ebook Central version].
5. Mager, D. (2017). How to have difficult conversations. Online Article *Psychology Today*. Retrieved from <https://www.psychologytoday.com/us/blog/some-assembly-required/201703/how-have-difficult-conversations>
6. Polito, J. (2013). *Effective Communication during Difficult Conversations*. *The Neurodiagnostic Journal*, 53(2), 142–152.



Dr. Jeffrey Holmes PhD., Associate Professor.



Abigail Reid, MSc Student, School of Occupational Therapy Western University

Visit **pssso.ca** to find out about:

- Parkinson's and Parkinson's programs
- Upcoming events, conferences and workshops
- How you can help
- Corporate/Employee involvement
- Sign-up to receive Enews updates
- And more ...

PSSO ANNUAL GENERAL MEETING

LOCATION:

Parkinson Society Southwestern Ontario
123-4096 Meadowbrook Dr, London
Wednesday, April 27 at 5:00 pm

RSVP at shelley.rivard@pssso.ca

Dance Training With Music Can Slow the Progression of Parkinson's Disease

A new study published in Brain Sciences shows patients with mild-to-moderate Parkinson's disease (PD) can slow the progress of the disease by participating in dance training with music for 1¼ hours per week. Over the course of three years, this activity reduced daily motor issues related to balance and speech, which often lead to social isolation.

Joseph DeSouza, senior author, principal investigator and associate professor in the Department of Psychology at York University and PhD candidate Karolina Bearss, found people with Parkinson's (PwPD) who participated in weekly dance training had less motor impairment and showed significant improvement in areas related to speech, tremors, balance and rigidity compared to those who did not do any dance exercise. Their data showed significant improvements in experiences of daily living, which include cognitive impairment, hallucinations, depression and anxious mood such as sadness. The study showed overall that non-motor aspects of daily living, motor experiences of daily living, motor examination symptoms and motor complications did not show any impairment across time among the dance-trained PwPD group compared to PwPD who did not dance.

The study is the first of its kind to follow PwPD over a three-year period during weekly dance participation with music. It provided additional information regarding the nature of progression of motor and non-motor PD symptoms

For more information about the study, go to <https://www.news-medical.net/news/20210707/Dance-training-with-music-can-slow-the-progression-of-Parkinsons-disease.aspx>

"The experience of performing and being in a studio environment with dance instructors appears to provide benefits for these individuals. Generally, what we know is that dance activates brain areas in those without Parkinson's disease (PD). For those with PD, even when it's mild motor impairment, can impact their daily functioning - how they feel about themselves. Many of these motor symptoms lead to isolation because once they get extreme, these people don't want to go out. These motor symptoms lead to further psychological issues, depression, social isolation. Eventually the symptoms do get worse over time. Our study shows that training with dance and music can slow this down and improve their daily living and daily function."

— Joseph DeSouza, Senior Author, Principal Investigator and Associate Professor, Department of Psychology, York University



Brianna Moretti

Certified Member, British Association of Teachers of Dancing, Dance London

DANCING WITH PARKINSON'S

In partnership with Dance London, Parkinson Society Southwestern Ontario is excited to announce that Dancing with Parkinson's will be offered as a pilot program in London at Dance London.

Dance classes for people with Parkinson's are designed to be safe, accessible and beneficial. Physical and cognitive limitations are not barriers to participation.

For more information, email Mandy at info@psso.ca or call 1-888-851-7376 ext. 204.

Assistance for Funding Needs

When my grandfather was first diagnosed with Parkinson's Disease (PD), it became apparent to me that there are many hidden costs that come with the diagnosis. Individuals who have PD may need a wide range of support for personal assistive devices and modifications to house and vehicle. Although these support options for individuals with PD may be expensive, luckily there are organizations that provide funding and support for individuals who may need financial assistance to obtain these support options and improve quality of life.

March of Dimes

March of Dimes Canada (MODC) is a national charity organization committed to empowering and creating real change for the 6 million Canadians living with PD and other disabilities with the goal of improving their quality of life. March of Dimes Canada provides several programs and services that can help with funding for individuals with PD, providing those in need with a variety of other benefits. These programs and services that would be beneficial to individuals with PD include the March of Dimes Canada Assistive Devices Program and the Home & Vehicle Modification Program.

The MODC Assistive Devices Program assists adults with physical limitations who need financial support to purchase assistive devices that can help improve their mobility and functional independence. The MODC Assistive Devices Program also helps to buy, repair and maintain a wide array of mobility and assistive equipment. The program also may help individuals find additional funding or resources.

The MODC Home and Vehicle Modification Program assists individuals to pay for renovations to their home or vehicle to allow them to have the independence to come and go as they please. This can give them the freedom to maintain a certain level of normality in life, such as keeping their job. The improvements can be made by widening doorways for a wheelchair, modifying a van or adding support bars so that an individual can bathe independently. Ultimately this financial assistance can allow individuals with physical disabilities to remain in their own home with their family. MODC Home and Vehicle Program not only supports large-scale renovations and retrofits for Ontario residents, but the MODC Home and Vehicle Program also provides some low-and no-cost modification options that help maximize independence on a minimal budget.

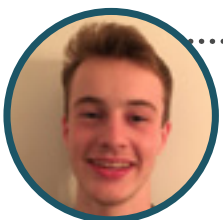
LINKS TO THE FOUNDATIONS/ORGANIZATIONS:

Ontario Assistive Devices Program:

www.ontario.ca/page/assistive-devices-program

March of Dimes Canada:

www.marchofdimes.ca/en-ca/programs



Samuel Kinsella is a fourth-year Political Science major at Western University. Sam is very interested in researching new and innovative treatments for Parkinson's and exploring financial programs to support those in need.

Ontario Assistive Devices

If you have a long-term physical disability, such as Parkinson's disease, you can get help paying for equipment and supplies if you qualify for the Assistive Devices Program. To qualify, an applicant must be an Ontario resident, have a valid Ontario health card and have a disability requiring the equipment or supplies for six months or longer. The Ontario Assistive Devices Program (OADP) covers 75% of the cost for equipment and supplies. For these items, the OADP is billed directly by the supplier. The recipient pays 25% when purchasing the item. Some of the equipment and supplies available to individuals with PD through OADP are mobility aids, hearing aids, visual aids and custom orthotic braces.

As a result of the COVID-19 pandemic, the Assistive Devices program is only accepting applications for funding assistance through email for grants, or fax for devices. In some cases, you receive a series of payments throughout the year to help cover the cost of supplies. Some examples of things **not** covered by the program that would be useful are automobile modifications, bath and shower aids (e.g., benches, chairs, batch lifts), lifting devices (e.g., chair lifts), diapers, smoke detectors, fire alarms, grab-bars, home renovations (including ramps, porch lifts, etc.), hospital beds and mattresses, incontinence supplies, life-alert systems, raised toilet seat, stair lift, standard walking canes and wheelchair ramps.

Deep Brain Stimulation and Brian Yundt's Story

Deep Brain Stimulation (DBS) is an invasive surgery for individuals with various neurological disorders usually in relation to movement. These symptoms, such as essential tremor, varying Parkinson's disease (PD) induced symptoms and dystonia have been treated over 160,000 times to date. The typical procedure involves implanting an electrode into the target region of the brain most effective at reducing the symptoms of that individual. This electrode is then connected to a pacemaker-like generator which rests in the upper chest, just underneath the collarbone of the patient. The generator can then be controlled in different ways (usually via Bluetooth) with a remote device which the individual can carry with them. For individuals with Parkinson's disease, this surgery is commonly utilized when medications are no longer effective to maintain good quality of life and result in polarized swings between their "On" and "Off" states.



Brian Yundt, now 45, was diagnosed with early-onset PD five years ago. Up until this August, he had been declining quite significantly. His quality of life seemed to be dissipating rapidly as his symptoms of dystonia and bradykinesia (slowed movement) without medication were severe. Brian was having to wake up hours before work in the morning to stretch and be ready. While he was able to function with the medication, he would struggle with dyskinesia (excessive movement from the medication) and random bouts of dystonia quite often. If he missed his pill time by five minutes the dystonia would return almost immediately. There were many times when he would be driving and would have to pull over to the side of the road as his leg began to cramp. He was unable to effectively press the gas or brake pedal. As his response to the medication was also waning (he gradually went from one pill every four hours to one pill every hour), he was open to any potential treatments to hopefully retain even a fraction of the quality of life he had before PD.

PD-induced symptoms such as tremor, rigidity, stiffness, dystonia and bradykinesia are reduced by disrupting abnormal electrical signals by activating the electrode implanted in the DBS procedure. This treatment is very flexible. Electrodes can be placed on one side or both sides of the brain. The generator in the chest can then be adjusted and programmed to the frequency most effective at reducing PD symptoms while minimizing potential side effects. Just like any other surgery, DBS carries a low risk of complications. Nevertheless, a joint decision should always be made by patients and their doctors regarding whether to undergo the surgery, as different individuals have different levels of susceptibility to complications or side effects. This causes certain eligibility criteria for receiving DBS. For example, someone with evident cognitive decline (another potential symptom of PD) may not be eligible for DBS, as there is a potential for the surgery to result in further cognitive decline. Therefore, it may not be worth the risk. These decisions are made in collaboration with the neurologist, psychiatrist and neurosurgeon as to whether DBS is the best option. Once a joint decision is made to undergo the surgery, the patient may first go through a neuroimaging scan (MRI or CT) to map the patient's brain and identify the optimal region where to place the electrodes. Patients are also observed when they are completely off medication to see the full extent of their PD symptoms.

Brian has been healthy and active throughout life and he had no cognitive decline throughout his five years with PD. After completing cognitive and psychological tests and the physical test when he was completely off medication, it was determined that he met all the criteria for being a good candidate to receive DBS. He specifically recalls how tough it was being off medication: "I couldn't even walk, they had to push me in a wheelchair. I was cramping everywhere (dystonia) and was sweating ... It was terrible."

"I couldn't even walk, they had to push me in a wheelchair. I was cramping everywhere (dystonia) and was sweating ... It was terrible."

— Brian Yundt

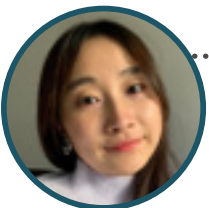
During the surgery, the patient is injected with a local anesthesia in the scalp. There are no pain receptors in the brain once past the scalp, so any implants or insertions of electrodes into the brain are painless. This allows for surgeons to actively test the effectiveness of the electrodes and have the patient actively respond. In other cases, a general anesthesia will be used, causing the patient to be fully unconscious. In the second portion of the surgery, the pacemaker-like generator will be placed under the skin in the chest.

On the day of the surgery, Brian had to be completely off medication. This is necessary so the surgeons can ensure that the electrodes are working and that an improvement in symptoms, or the degree of effectiveness, is not caused by medication. He was awake and responsive for the procedure as the surgeons implanted the electrodes into the optimal positions. He remembers being told not to talk as his speech was activating neurons in his brain and distorting the signals the surgeons were analyzing to test the effectiveness of the electrodes in the positions in which they placed them. The generator in his chest connects to his phone using Bluetooth and he can now easily adjust the electrode stimulation levels if needed.

Having a realistic expectation of the surgery is important when deciding whether to undergo the surgery. While deep brain stimulation doesn't cure Parkinson's disease, it can help lessen symptoms tremendously. The improvement of symptoms depends on individuals, so it is necessary for patients to discuss with their care team the expectations for the surgery.

Brian is practically a best-case scenario, but his experience exemplifies the life-changing potential DBS has. Before the surgery, he didn't know what his future would be for his career or how his life would be with his wife. He was having to live on a day-to-day basis, as his dystonia controlled his life and prevented him from making simple plans for the next week or even the next day. Now, after the surgery on August 23, 2021 and his final programming session in November (to optimize the generator and level of electrode stimulation), his life is completely back to normal. His dystonia, bradykinesia and dyskinesia are all gone and there are no swings of mobility or unpredictable cramping throughout his day-to-day life. He can workout again and go out to dinner with his wife confidently and with no anxiety. As December approaches, he is on the verge of returning to his job as a manager for building inspectors. While he doesn't know what will happen years down the road, right now his life has been restored to a degree to which he would have never thought possible six months ago. While he is aware that DBS might not be effective for everyone, he still wants people with PD who may be eligible for the surgery to be aware of it and consider its potential. It has completely changed his life and it certainly has the potential to change others as well.

A special thanks to Brian for taking the time to talk about his experiences with Parkinson's, his DBS surgery and how his life has changed since.



Yunyi Yan is a third-year Kinesiology and Psychology double-major student. She is passionate about neurological disorders and hopes her work can help people.



Simon Hawke is from Vancouver, B.C. He is currently in his third year at Western University studying neuroscience and is interested in researching neurodegenerative diseases.

What to Know About Hallucinations, Delusions and Obsessive Compulsive Disorder in Parkinson's Disease

Hallucinations

Hallucinations are a distressing and often unsettling feature of Parkinson's disease, experienced by about 20-40% of people.¹ The reported types of hallucinations are:

- Visual
- Auditory
- Olfactory (sense of smell)
- Tactile
- Gustatory (sense of taste)

Visual hallucinations are the most common and can appear as having vivid visions of an old pet, lost loved one or even flashes of light. Surprisingly, the main source of the hallucinations is the medications used to treat Parkinson's.⁹ Levodopa and dopamine agonists are used to treat tremors, stiffness and slow movements, which are characteristic symptoms of Parkinson's disease.⁸ These symptoms are a result of a lack of dopamine in the brain, so levodopa and dopamine agonists work to increase the levels of dopamine and mimic its effects in the brain respectively.^{8,3} This increases the sensitivity of the part of the brain that produces dopamine, which unfortunately contributes to hallucinations.⁹

Experiencing this sense of distorted reality can be frightening for both the person with Parkinson's disease and their loved ones. On a more positive note, most cases of hallucinations are short-lived and non-threatening.³ They are also manageable by ensuring there is good lighting in the evenings when hallucinations are likely to occur and practising relaxing, less stimulating activities before bed.³ It is important to express any concerns regarding these hallucinations with your doctor.

Delusions

Delusions, along with hallucinations, are considered part of Parkinson's disease psychosis. Less common than hallucinations, delusions are only prevalent in 8% of people with Parkinson's disease.² Delusions are another way the brain can play tricks on people by forming irrational and nonsensical thoughts.⁴ At the beginning, delusions can be considered to be confusion at nighttime and sadly this can progress into vivid delusions and behavioural disturbances in the daytime.⁴ The reported types of delusions include:

- Jealousy or possessiveness
- Persecutory
- Somatic
- Guilt

Jealousy and possessiveness delusions can lead people to think someone is being unfaithful or disloyal, and to become paranoid or agitated.^{2,4} **Persecutory** delusions cause people to think someone is going to harm them so the person may become socially withdrawn or paranoid.⁴ **Somatic** delusions occur when a person thinks they are injured or that their body is functioning in an irregular way. They may become obsessed with their health-concerning symptoms and visit their doctor often.⁴ **Guilt** delusions cause a person to experience feelings of guilt or shame, but these feelings are not grounded in actual behaviours or actions.² People with Parkinson's disease can also experience mixed delusions where they go through more than one type of delusion at once. The most common form of delusion is jealousy and persecutory, which can present a safety concern to the person with Parkinson's disease and their family if they become aggressive.⁴

In the same mechanism that causes hallucinations, the medications to treat the motor symptoms of Parkinson's disease are the trigger of delusions. Delusions are generally more complicated than hallucinations because of the higher risk of disturbances in behaviour such as aggression, safety risks and even refusal to take medications.⁴ Treatments exist for Parkinson's disease psychosis which improve both hallucinations and delusions. These involve adjusting dopamine medications and antipsychotic therapy to regulate the chemical levels in the brain.⁴

Obsessive Compulsive Disorder

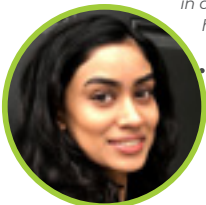
Obsessive Compulsive Disorder (OCD) is a condition in which a person has repeated unwanted thoughts or feelings which encourage them to do an action repetitively.¹⁰ This can include repetitive handwashing, cleaning or checking on things such as locks or switches. Anxiety and distress can result if the compulsion is resisted and not complete. These urges are persistent and interfere with one's daily activities and can disrupt social interactions.¹⁰

There has been growing research investigating the link between OCD and Parkinson's disease. Specifically, looking into how OCD may also involve the dysfunction of the basal ganglia just as Parkinson's disease does.⁷ The basal ganglia are a group of structures in the brain that are involved in activating motor and behaviour plans.⁶ In Parkinson's disease, the dopamine pathway, called the substantia nigra, in the basal ganglia is damaged. This leads to tremors, rigidity and slowed movements.¹ Because of this shared circuitry of a damaged basal ganglia, there is a higher incidence of OCD symptoms in people with Parkinson's disease.⁷

Various therapies exist to treat people with OCD in order to enhance their quality of life and functioning. Cognitive behavioural therapy has been used to treat OCD effectively. This entails exposing the person to a situation that involves their obsession.¹⁰ This allows them to build an initial level of anxiety. Then they are reassured that nothing terrible happens when they resist their compulsions. It is important to ensure that people with Parkinson's disease and OCD are reassured of their safety as it can be distressing to resist their compulsions.

References:

1. Blandini, F., Nappi, G., Tassorelli, C., & Martignoni, E. (2000). Functional changes of the basal ganglia circuitry in Parkinson's disease. *Progress in Neurobiology*, 62(1), 63–88. [https://doi.org/10.1016/s0304-0082\(99\)00067-2](https://doi.org/10.1016/s0304-0082(99)00067-2)
2. Cafasso, J. (2020, December 3). Parkinson's hallucinations: Delusions and more. Healthline. Retrieved December 7, 2021, from <https://www.healthline.com/health/parkinsons-and-hallucinations#delusions>.
3. Ghoshal, M. (2019, December 6). Dopamine agonists: Common uses, side effects, and more. Healthline. Retrieved December 7, 2021, from <https://www.healthline.com/health/parkinsons-disease/dopamine-agonist>.
4. Hallucinations/delusions. Parkinson's Foundation. (n.d.). Retrieved December 7, 2021, from <https://www.parkinson.org/Understanding-Parkinsons/Symptoms/Non-Movement-Symptoms/Hallucinations-Delusions>.
5. Heilbron, K., Noyce, A. J., Fontanillas, P., Alipanahi, B., Nalls, M. A., & Cannon, P. (2019). The parkinson's phenotype—traits associated with Parkinson's disease in a broadly phenotyped cohort. *Npj Parkinson's disease*, 5(1). <https://doi.org/10.1038/s41531-019-0077-5>
6. Huey, E. D., Zahn, R., Krueger, F., Moll, J., Kapogiannis, D., Wassermann, E. M., & Grafman, J. (2008). A psychological and neuroanatomical model of obsessive-compulsive disorder. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 20(4), 390–408. <https://doi.org/10.1176/jnp.2008.20.4.390>
7. Nicoletti, A., Luca, A., Raciti, L., Contrafatto, D., Bruno, E., Dibilio, V., Sciacca, G., Mostile, G., Petralia, A., & Zappia, M. (2013). Obsessive compulsive personality disorder and Parkinson's disease. *PLoS ONE*, 8(1). <https://doi.org/10.1371/journal.pone.0054822>
8. U.S. National Library of Medicine. (n.d.). Levodopa and carbidopa: Medlineplus Drug Information. MedlinePlus. Retrieved December 7, 2021, from <https://medlineplus.gov/druginfo/meds/a601068.html>.
9. Weil, R., & Reeves, S. (2020). Hallucinations in Parkinson's disease: New insights into mechanisms and treatments. *Advances in Clinical Neuroscience & Rehabilitation*, 19(4), 20–22. <https://doi.org/10.47795/onns5189>
10. What Is Obsessive-Compulsive Disorder? What is obsessive-compulsive disorder? (n.d.). Retrieved December 7, 2021, from <https://www.psychiatry.org/patients-families/ocd/what-is-obsessive-compulsive-disorder>.



Miranda Rodrigues is from Mississauga and is currently in her third year at Western University. Miranda is enrolled in the Health Sciences program with an Honours Specialization in Rehabilitation Sciences.



WHO WILL YOU WALK FOR?

Walk for Parkinson's Is Back - September 10 & 11

Join the PD community this September 10 or 11 at our annual **Walk for Parkinson's** to raise funds and awareness for people living with Parkinson's disease. We are thrilled to be planning for a return to in-person walks, and with that, all of the fun and engaging activities you have come to enjoy from previous years. Come for the walk, but stay for the fun, music, refreshments, and of course social interactions that we have undoubtedly missed. Unable to walk in person? No problem – join the online virtual **Walk for Parkinson's** and walk your own way! We look forward to seeing all of you this September!

Gather your family, friends and get your team ready to go!

PSSO will follow all local health regulations in place during these events.

walkforPD.ca

Tips for an Emergency Room Visit

A sudden visit to the hospital at any time of day or night can be all in the course of a day's work for family caregivers. Whether you're calling an ambulance or rushing someone to a local hospital, being prepared in a potentially overwhelming emergency situation is simply safer and less stressful.

First of all, having a clear list of what to do, along with having your loved one's latest healthcare information ready to provide to health professionals, can help improve both timeliness and quality of care. Review this checklist with your loved one and keep it handy for a time when it is urgently required.

What to Pack for the Hospital with Comfort in Mind

Hospitals often encourage patients and their families to bring other items to help make a hospital stay more pleasant or comfortable. Hospitals provide gowns and toiletries, but they generally invite patients to bring their own pajamas, bathrobe, cardigan sweater, non-slip socks or slippers, comb, brush, lotions, toothbrush, toothpaste and lip balm. However, avoid perfumes and any highly-scented products. Keep in mind that short sleeves are best to accommodate intravenous lines.

Check ahead of time to find out what the hospital will allow. This information often can be found on the hospital's website. Consider:

- Protective containers for holding eyeglasses or dentures when not in use
- Books, magazines and crossword puzzles to help pass the time
- Paper and pen for jotting down notes and questions
- Clothing to wear home at discharge
- A small amount of money for newspapers, magazines and other items from the gift shop or vending machines
- Cell phone and charger

What Not to Pack

Hospitals are not responsible for patients' personal belongings so it's best not to bring valuables. Specific things to leave off the packing list:

- Tobacco because smoking and recreational drugs are prohibited in healthcare facilities
- Credit cards, cheque books, large amounts of cash, jewelry, high-end portable music players and other valuables such as electronic devices like iPads or computers

What to bring:

- Photo ID
- Your government health insurance card
- A list of all the medications (prescription and over-the-counter) your loved one is currently taking at home, along with dosage. Keep it somewhere easily accessible, such as in your wallet or wherever you keep your health card.
- A copy of advance healthcare directives, such as power of attorney for personal care and their living will
- A personal health record that includes information such as operations, allergies, health conditions, immunization record and reports of recent tests or physical exams. At times, it can be difficult to explain your medical history or trial and error with treatment options to the nurses and doctors while visiting the ER.
- Reports your physician gave you to bring to the hospital and latest bloodwork
- A list of telephone numbers of family and friends to be contacted as needed

To avoid misplacing any of this important paperwork and information - which is critical for facilitating a patient's treatment - keep it all together in one folder.

Be patient. The wait times in the ER can be long and it's a good idea to have someone stay as an advocate to speak on your behalf if you are too ill to represent yourself.

Keep track. Write down immediate concerns, along with names of doctors and specialists. Ask what tests and procedures are possible, are being done and why. Before you sign any consent forms for a procedure, make sure you read and understand what you are giving consent for. Don't be afraid to ask questions like, "Why do I need to have this procedure?" and "What are you recommending as follow-up?"

Limited wifi or cell service. Some hospitals have restricted access to services. If you need to contact people to assist you or inform them of your situation, try to do so before entering the hospital.

Dress accordingly. Loose fitting, comfortable pants and shirts make it easier for waiting family members, patient examinations, changing into a hospital gown, blood work and other possible tests.

Try your best to remain calm. Be honest about your loved one's pain levels and symptoms. Be kind and reasonable. Recognize that ERs are constantly in flux, busy places where most urgent cases are usually handled first.

Interpreter services. Many hospitals offer on-site, in-person interpretation for many languages, including ASL (sign language). If you or your family member would feel more comfortable speaking in another language, you can make a request for an interpreter. In an emergency or short-notice situation, when an in-person interpreter may not be immediately available for the language you request, the hospital may need to use telephone and/or video remote interpretation.

By Kylie MacKenzie

Source: <https://www.caregiversolutions.ca/top-stories/are-you-911-ready/>



To leave a legacy is to sew seeds for the future. To leave a legacy is to ensure that access to support services and educational opportunities remain available. To leave a legacy is to ensure others that come after you have the opportunity to fight and live better with Parkinson's.

We all want a world without Parkinson's, but until that day comes, we remain ready, able and willing to support the needs of today. A legacy gift makes that work possible.

Email shelley.rivard@psso.ca
or call 1-888-851-7376 for more
information on leaving your legacy.



THANK YOU for raising over \$327,000!



Walk for Parkinson's 2021 Rocked Southwestern Ontario

We were socially distanced, wore masks, sanitized everything and walked in small groups. Yet despite everything COVID-19 tried to throw at us this year, we were POSITIVE and SUCCESSFUL! One community even had a tornado try to disrupt its' walk. Through it all, our Parkinson's supporters were resilient, optimistic and persistent, taking up the challenge to support services and research.

Money wasn't the only thing raised. In communities throughout Southwestern Ontario, PSSO clients, families and carepartners raised awareness about Parkinson's, by standing up and letting their friends and neighbours know that while they might have Parkinson's, it didn't have them. So what's next?

Planning has already begun for the 2022 **Walk for Parkinson's**. Stay involved throughout the year by volunteering to sit on local walk committees, starting your fundraising early or thinking about who will be on your walk team this year (and getting them to start walking with you for exercise). If you have ideas or questions, contact us at events@pssso.ca.

Remember ... every dollar raised through **Walk for Parkinson's** goes towards programs and research that benefit Parkinson's clients throughout Southwestern Ontario. See you September 10th and 11th.

TOP WALKERS

| | |
|-------------------------|----------|
| Clare Poechman..... | \$11,441 |
| Chad McGahan..... | \$9,518 |
| Robert Ecclestone | \$9,080 |
| Scott Dunbar..... | \$8,196 |
| Grant Bourner | \$6,796 |
| Bill Schafer | \$6,361 |
| Stuart Selby | \$6,357 |
| Bob McMillan | \$5,623 |
| Mary Vernon | \$5,581 |
| Carolyn Young | \$5,111 |

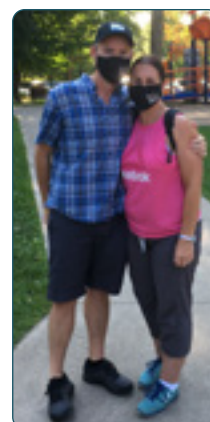


2021

WALK for Parkinson's Sponsors



ABC Investments, Action Health Care, Bluewater Power Distribution Corp, Boshart Industries Inc., Commonwealth Financial Inc., Core Fuels Ltd., D'Arcy DW Bell Prof Corp, Egremont Optimist Club, Enterprise Holdings Foundation, Fisher Professional Corporation, Gates Canada Inc., Gateway Casinos & Entertainment Ltd., Georgian Bay Cremation Services, Germania Mutual Insurance, H T & C Mutual Insurance, JASLO Properties Ltd. (aka Strathroy Mini Storage), Kent & Essex Mutual Insurance Co., KWIC Internet/NCS Technologies, Nicol Insurance, North Kent Mutual Insurance, NPX Innovation, Physiotherapy on Front, Port Elgin Veterinary Clinic, Re/Max Bluewater Realty Inc., Roulston's Discount Drugs Ltd., Troy Life & Fire Safety Ltd., Unifor Local 2458, Unifor Local 88, Windsor Factory Supply Ltd., Windsor Firefighters Benefit Fund.



Volunteer Profile: Rachel Lee and Casey Salema

In May 2021 we began our second placement opportunity through Western University's Master of Science in Occupational Therapy program, working within a day program called "Enhancing Participation: A Parkinson's Program" offered out of Elborn College. This program ran for eight weeks where students from Western's rehabilitation sciences graduate programs, including occupational therapy, physical therapy, speech language pathology and audiology, provided virtual care to clients in Southwestern Ontario.

As occupational therapy students, our role involved working one-on-one with clients and their carepartners to collaboratively identify any barriers that may be impacting their quality of life due to Parkinson's-related symptoms, and finding creative ways to best support and optimize their continued engagement in their chosen meaningful activities of daily living. Through this program, we had the privilege of creating personalized treatment sessions that focused on topics including education on falls, risk and management strategies, home safety assessments and modifications, energy conservation strategies, and the role and use of assistive technology.

This opportunity not only afforded us an enriching learning opportunity, but it also gave us a glimpse into the Parkinson's community that exists in Southwestern Ontario. Despite providing care through a virtual platform, our clients and their carepartners embraced us as student occupational therapists, and welcomed us to explore their journey with Parkinson's disease and collaborated to identify ways to support and enhance their quality of life. Through this experience, we learned about what encompasses a Parkinson's diagnosis, and more importantly who our clients were and how occupational therapy as a profession could support their needs and goals. We learned about their families, jobs and hobbies, along with how their diagnosis was affecting their daily living. This placement experience and most importantly, our clients, have helped us realize that while it is imperative to continue to learn about the symptoms, management and treatment of Parkinson's disease, the most important part is to learn about the person who is living with the diagnosis.

Above all, we gained insight into the positivity and perseverance of this community. Through each identified barrier or challenge, our clients demonstrated determination and dedication to continue to participate in the activities that meant the most to them. Their continued willingness to share and collaborate, coupled with their eagerness and enthusiasm to learn and participate in therapy, made each interaction incredibly valuable and meaningful for us as student occupational therapists.



Student Occupational Therapists, Elborn College, "Enhancing Participation: A Parkinson's Program". Rachel Lee (Left) and Casey Salema (Right)

On September 11, 2021, we had the opportunity to volunteer with Parkinson Society Southwestern Ontario (PSSO), as we took part in supporting the annual Walk for Parkinson's hosted at Springbank Gardens. It was through this experience that our eyes were opened to the strong and caring Parkinson's community here in London. It was inspiring to see individuals with Parkinson's disease come together to support one another, raise awareness and advocate on behalf of themselves and their family members and friends.

The confidence and trust displayed by our clients and those within the Parkinson's community will continue to resonate with us as we continue through our journey to become licensed occupational therapists.

We are extremely appreciative to have experienced both providing direct occupational therapy education and care to clients and their carepartners, as well as getting the opportunity to interact with individuals living with Parkinson's disease during **Walk for Parkinson's**. This volunteer experience provided us the opportunity to reflect on specific intervention strategies that we had provided to our clients via a virtual platform and recognize areas for future growth in providing client-centered care to individuals with Parkinson's disease. It is our hope to continue engagement with the Parkinson's community through future events and in occupational therapy practice.

Thank You!

We wish to express our appreciation to the James Goreski Private Foundation for their generous support of Parkinson's programs in Grey-Bruce counties. A grant made by the James Goreski Private Foundation will be used towards hosting the Spring Regional Parkinson's Conference in Walkerton on May 7, 2022. Please join us in thanking them for their kindness and generosity.



In Memoriam

We offer our sympathy to the families whose loved ones have passed away between July 1, 2021 and December 31, 2021.

Jean Ahrens
Morley Aitken
Peter Allen
Wayne Allen
Helen Allin
Marilyn Armstrong
Gerald Atkinson
John Averell
Said Awad
Freeman Bamford
Eila Belanger
Jean Berdan
Eldon Black
David Botterill
Lymand Bowen
Douglas Brown
Vera Brown
Maria Brusco
Dr. Bill Bryant
Anne-Marie Cadogan
Don Camick
Robert Coleman
Donalda Connor
Lois Courtney
Gary Dale
Glenn Dalgleish
Vernon Keith Davis

Donald Dye
Doreen Ecclestone
Rosalie Eggenschwiler
Michael Etzkin
Guy Fader
Ronald Fink
Kenneth Foulis
Nauta Frank
Burrell Gailing
Brad Garlick
Allan Garner
Leila Garner
Greg Gavan
George Gibbons
David Gilbert
Ruth Ann Gilbert
Allan Goebel
Dianne Griffith
Gaspere Grillo
Douglas Hammar
Kenneth Harris
Dianne Harron
Bernie Hartman
Harvey Hennessy
Carman Hodgkinson
Franco Imola
Katherine Irwin

Frank Ische
Dave Jackson
Jessie Johnson
Joe Kelly
George Kemick
James Kerrigan
Donald Kesselring
Joyce Kirby
Marjorie Kraft
Audrey Latsch
Robin Lauzon
Stephen Leach
Olive Leatherdale
Joe Malo
James Maloney
Maureen Mansfield
Shirley Marriott
Doris Matheson
Yvonne Mazer
David McCalden
Cora McCann
Timothy McEllister
Isabel McKeen
Peter Mersch
Donald Miller
Elizabeth Moffatt
Shirley Morris

Francelina Moura
Jim Muzzell
Kevin Oakley
Norman Osborne
Stewart Parsons
Donna Patterson
Anthony Piron
Robert Prince
Wilda Renwick
Theresa Rizzo
Thomas Robbins
Karl Row
Larry Schaefer
Carl Schroeder
Ralph Shelton
James Siler
Pearl Small
Francis Smith
Randall Spencer
Garry Sproule
Robert St. Laurent
Margaret Stanley
Robert Stevenson
Larry Stewart
Mira Stojcevski
Martin Taylor
Tom Thompson

Judy Thoms
Charles Thorpe
John Thrasher
Marilyn Topham
Ted Torelli
Mary Turner
Lloyd Turney
Rudy Van Holland
Myrtle Varga
Doreen Veach
Bauke Vogelzang
Lois Wagstaff
George Walker
Rose Wallace
James Wardell
Shari Weaver
Gary Welch
Robert Welsh
William Werezak
Virginia Whitehead
Gail Wiegand
Anna Wieleman
Stephen Williams
Peter Wilson
Paul Wilton
Robert Young

We make every effort to include all members who have passed away. We sincerely apologize if any individual was inadvertently omitted from the above list. Please call and let us know if we have missed anyone and we will include their name in our next issue.



April is Parkinson's Awareness Month

I Love Someone with Parkinson's celebrates the person living with Parkinson's. Our true heroes. Whether it's you, a family member, a co-worker or a friend with Parkinson's, let everyone know you care!

How Can I Spread the Word?

- Display the "I Love Someone with Parkinson's" poster in your window
- Share your story or create a video
- Share tips on living better with Parkinson's
- Follow us on Facebook and Instagram. Post your pictures and add the hashtag **#ILoveSomeoneWithParkinsons**

How do I Recognize World Parkinson's Day on April 11?

- Celebrate by joining our virtual Coffee Klatch at 10:00 am
- Spread awareness by contacting your local MP or MPP

Help us spread awareness by showing the world you care!

Visit our website for more information and updates at pssso.ca

parkinson SOCIETY
SOUTHWESTERN
ONTARIO

[f ParkinsonSocietySWO](https://www.facebook.com/ParkinsonSocietySWO) [@parkinsonswo](https://www.instagram.com/parkinsonswo)