



THE PARKINSON'S UPDATE

WINTER/SPRING 2021 · ISSUE 73

**Research
Update**

Page 3

**The PSSO
Parkinson's Choir**

Page 12

**Is it Time for a
Nursing Home?**

Page 14

MISSION STATEMENT

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

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Manager, Fund Development

Lisa Nixon
Information and Referral Specialist

Mark Womack
Community Development
Coordinator - Grey Bruce

Front Cover Photo:

Sophia Christopher runs the free Parkinson's Music Choir. Parkinson Society Southwestern Ontario has piloted the choir designed specifically to address and meet the needs of individuals experiencing Parkinson's. For more information, go to page 12.

FROM THE CEO'S DESK

Well we made it. Welcome to 2021! I am not sure how you thought 2021 was going to begin. For me, it is much different than I was anticipating. However, with the vaccine on the horizon, I hold onto the hope that there is light at the end of the tunnel and a big hug waiting, that many of us have so missed.

We want you to **begin 2021 well**, and we're here to help. We will be focusing on ways we can begin well in mind, soul and body. Resources will be made available on our website.

Our programs have begun, Support Groups, Louder, Clearer, Music Choir. We have also launched a new program, our Newly Diagnosed Series, which is designed to support those at the start of their Parkinson's journey. We are always here to help get you connected to resources in your local community and lend an ear in those tough times.

We are excited about our Living Well Spring Virtual Conference in April. Our keynote speakers, Dr. Soania Mathur and Larry Gifford, will share with us how we can break the silence and join the global alliance of people with Parkinson's, partners and friends, standing together to demand change in how Parkinson's is seen and treated. The PD Avengers are **United to end Parkinson's**. We also have Dr. Jessica Grahn, Dr. Akshya Vasudev and Karen Van Ooteghem. (see page 6 for more information)

As well as the Graduate Student Scholarship Awards, we have begun a new award, the Clinical Movement Disorder Fellowship Program. This program is to provide expertise in diagnosis and management of Parkinson's in a clinical setting through hands-on experience. We look forward to receiving applications for both of these awards in the coming days.

As we proceed into 2021, we will have lots of exciting news to share – so keep connected. Stay safe and healthy! We look forward to seeing you in person soon.



Shelley Rivard



Shelley Rivard
CEO

Our Research



The London Movement Disorders Centre Brain Bank

Patients who are part of the London Movement Disorders Centre are eligible to consider donation of brain tissue upon passing. This is possible only for those who are patients of the clinic and have been followed regularly at the clinic.

Parkinson Society Southwestern Ontario awarded \$96,000 for the establishment of the Brain Bank for Parkinson's. For more information on the brain bank, contact Lisa Nixon at info@parkinsonsociety.ca.

Clinical Movement Disorder Fellowship Program



Parkinson Society Southwestern Ontario (PSSO) is excited to offer its Clinical Movement Disorder Fellowship Program as a strategic initiative to encourage young clinicians to enter the field of clinical training in Movement Disorders, specializing in Parkinson's disease. This award in the amount of \$50,000 is to provide expertise in diagnosis and management of Parkinson's disease in this hands-on program.

Graduate Student Research Program

Parkinson Society Southwestern Ontario Graduate Student Scholarship Program is a strategic initiative to encourage young scientists to enter the field of Parkinson's research and to invest in research and training that offers promise for future work in the area of Parkinson's disease. PSSO provides awards up to \$25,000 each year to outstanding graduate students who meet the eligibility criteria of the program and who have been approved by the Program's Adjudication Committee.

"Science and the development of new ideas and thoughts is the golden rule for innovating better and important therapies. This is especially true for the brave new world of neurodegenerative disorders as we understand them today. Graduate students that support this mandate are absolutely essential in providing the manpower and fuel. Without funding for these students, scientific advancement would grind to a halt. The role of funding agencies is to foster and inculcate these young minds so that the future of science in studying Parkinson's disease remains bright." Dr. Mandar Jog



Regional Office:

117- 4500 Blakie Rd., London, ON N6L 1G5
 Phone(519) 652-9437
 Toll Free..... 1-888-851-7376
 Fax.....(519) 652-9267

✉ info@parkinsonsociety.ca
 🌐 www.parkinsonsociety.ca
 📌 [ParkinsonSocietySWO](#)
 📷 [parkinsonswo](#)

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.

OUR PROGRAMS & SERVICES



INFORMATION & REFERRAL

Have a question about Parkinson's? Are you looking to join a support group, speech or exercise program? Need help finding information or accessing services in your local community? Information and Referral is all about bringing people in need together with the services in their community.

Contact Parkinson Society Southwestern Ontario at 1-888-851-7376 or email info@parkinsonsociety.ca.

NEWLY DIAGNOSED SERIES

Were you diagnosed with Parkinson's in the last 24 months? Are you struggling with the diagnosis? Would you like to learn more about Parkinson's? Are you unsure of the next steps, or having difficulty sharing the news with family and friends? The Newly Diagnosed Series is 4 sessions and is offered several times during the year.



COUNSELLING

If you're dealing with a new diagnosis of Parkinson's disease, need help sharing news with family and friends, if you have relationship issues, are dealing with grief, loss, depression or anxiety, we are here for you. FREE, short term, non-crisis counselling is provided by a Social Work Student through a partnership with King's University College. Counselling is available September to June.

Contact Parkinson Society Southwestern Ontario at 1-888-851-7376 or email counselling@parkinsonsociety.ca.

SUPPORT GROUPS AND EXERCISE PROGRAMS

Are you looking to join a support group or exercise program? There are a number of support groups throughout the region and specific groups for CarePartners and Young Onset as well as a number of exercise options like Rock Steady Boxing and Parkinson SMART.





COFFEE KLATCH

Have you ever wanted to meet other people from other areas around Southwestern Ontario? Grab your favourite drink - hot or cold, and meet us online to connect with each other! Coffee Klatch is Mondays at 10:00 am. Coffee Klatch is a German phrase to mean "a casual social gathering for coffee and conversation!"

PARKINSON'S MUSIC CHOIR

A fun, therapeutic and evidence-based approach to enhance respiratory function. Parkinson's Music Choir is 12 sessions and is offered a few times throughout the year.



LOUDER, CLEARER: A PARKINSON'S VOICE TRAINING PROGRAM

Group sessions are led by Speech-Language Pathologists to provide an opportunity for people with Parkinson's in Southwestern Ontario to learn and practice skills for louder, clearer speech in a relaxed and social atmosphere. Louder, Clearer program is 8 sessions offered online and in various locations throughout the year.



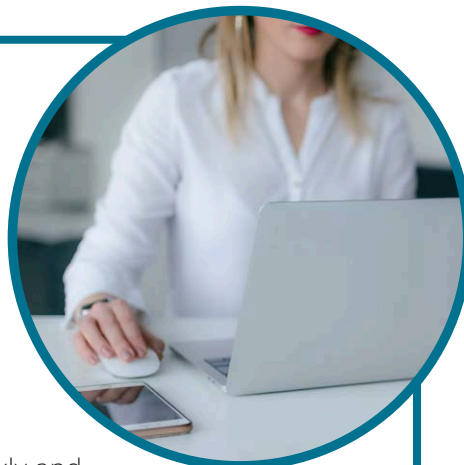
CONFERENCES, WEBINARS & WORKSHOPS

The Parkinson's conference takes place in the fall and usually alternates between London and Kitchener. Living Well Conferences are smaller venues and typically take place in the spring as part of April Awareness.

Webinars are scheduled throughout the year. Workshops may also be offered throughout the region or online.

PARKINSON'S UPDATE AND PARKINSON'S ENEWS

The Parkinson's Update newsletter comes out twice a year and is available in print and online. Parkinson's enews is weekly/biweekly and only available through email.



Parkinson's Lament

Written by Anthony Bender

This lament that I have written focuses on my journey with Parkinson's disease. There are things I do not like (despair) about having to live with it. However, I am thankful for many things. I do have a lot of hope.



Anthony Bender

I don't like what Parkinson's is doing to me.

At my worst times, and fortunately I hardly ever have these times, I wonder if it is worth it to keep going. I think it would be easier if I weren't here anymore. As I said, I hardly ever think like this. However, to say I never have would also not be true.

I am tired.

I am tired of my balance being poor.

I am tired of my feet shuffling.

I am tired of not being able to walk correctly anymore. I think everyone looks at me when I am walking. This is my problem. I sometimes think I am getting paranoid.

I am tired of telling people I don't feel well. However, I don't always want to say I am feeling well if I am not. I am sure this doesn't make sense, but sometimes I feel that I have failed.

I feel bad about what it has done to my primary relationship (my dear Connie).

I feel bad that we have both just retired and now we should be able to do all kinds of things together, but often I don't have the energy to do them. It would be great to go to movies, go to concerts, walk uptown and explore restaurants and entertain.

I feel bad about all of my losses before I should have to deal with them.

I am angry. I have my times when anger dominates my feelings. I just want to spit bullets.

I am afraid for the future. Will I be able to enjoy my retirement or will I just exist?

I feel really ripped off.

And yet as I live through the valleys of anger and grief, I know God that you are there and you are with me.



2021 LIVING WELL SPRING VIRTUAL CONFERENCE

MIND, BODY & SOUL

SATURDAY, APRIL 24, 2021
9:00 AM - 1:00 PM

KEYNOTE SPEAKERS

PD AVENGERS:

United to end Parkinson's Disease



Dr. Soania Mathur



Larry Gifford

PRESENTATIONS:

The Role of Non-Pharmacological Interventions in Late Life Mood Disorders and PTSD

Dr. Akshya Vasudev, MBBS, MD

Wearable Biosensors for the Management of Parkinson's Disease: Opportunities and Challenges

Karen Van Ooteghem, PhD Kinesiology, Neuroscience

Music and Mind: Exploring the benefits of Music

Dr. Jessica Grahm, PHD

COST:
\$30

SUPPORT
PROVIDED BY:

abbvie

For more information and to register, go to parkinsonsociety.ca

I wake up from dreams with the song 'When peace like a river - it is well with my Soul' singing in my head - where does that come from? Somewhere in the depths of my being there is a faith grounded in something that is much bigger than me.

I am thankful for the gift of each day that God grants me. I am thankful for each sunrise and sunset.

I am thankful for relatively good health. I am thankful for each day that I can still look after myself.

I am thankful for the ability to still be able to do exercises.

I am thankful that I can still play guitar.

I am thankful I can still drive.

I am thankful I can still swallow without any difficulty.

I am thankful I can still read.

I am thankful I can still volunteer.

I am thankful for all of my friends.

I am thankful for all the medical/health resources I have been able to access. I am thankful for neurologists, neurosurgeons and all the researchers who have developed neuro transmitters.

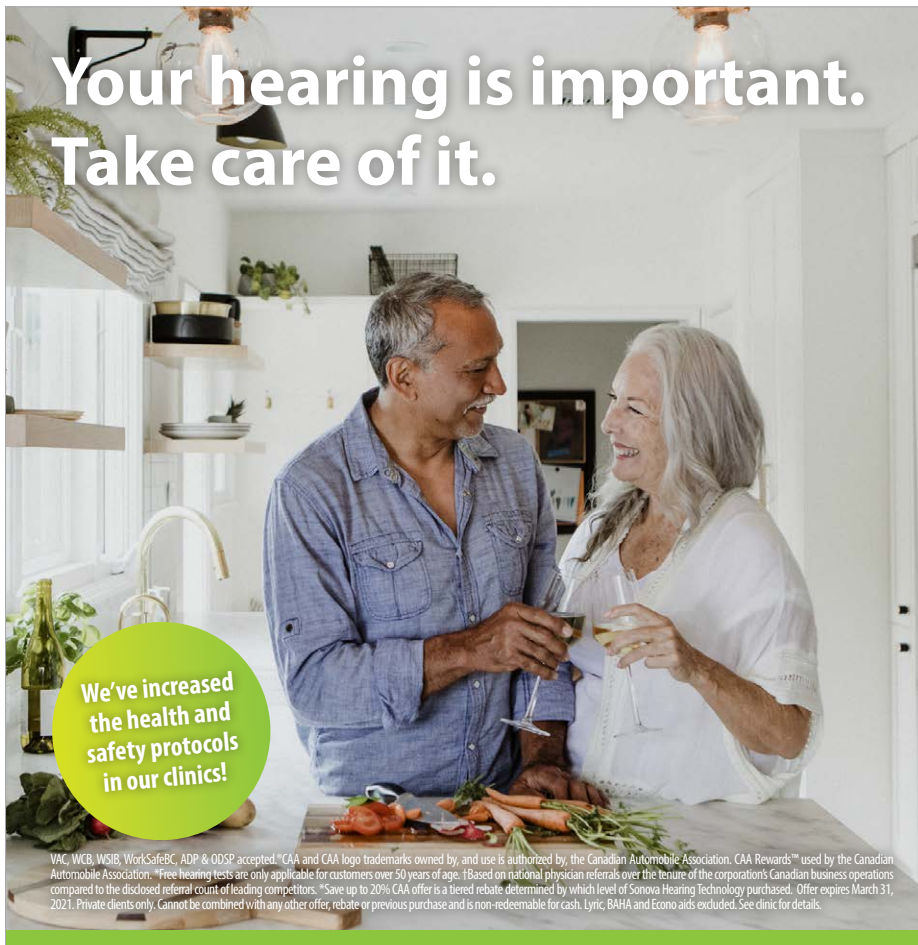
I am thankful for the resources at the MDRC (Movement Disorders Research and Rehabilitation Centre) at WLU. I am thankful I can participate in their research programs.

I am thankful for my faith. I am thankful that I can be part of a faith community.

Above all I am thankful for the gift of life with all its joys and challenges.

Through the struggles of living with the reality of a chronic illness, I know that Thou art with me - my Sanctuary.

Anthony Bender



Your hearing is important. Take care of it.

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VAC, WCB, WSIB, WorkSafeBC, ADP & ODSP accepted. *CAA and CAA logo trademarks owned by, and use is authorized by, the Canadian Automobile Association. CAA Rewards™ used by the Canadian Automobile Association. †Free hearing tests are only applicable for customers over 50 years of age. ‡Based on national physician referrals over the tenure of the corporation's Canadian business operations compared to the disclosed referral count of leading competitors. *Save up to 20% CAA offer is a tiered rebate determined by which level of Sonova Hearing Technology purchased. Offer expires March 31, 2021. Private clients only. Cannot be combined with any other offer, rebate or previous purchase and is non-redeemable for cash. Lyric, BAHA and Econo aids excluded. See clinic for details.

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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 APOMORPHINE?

Apomorphine is a dopamine agonist which means that it binds to the dopamine receptors. Although the name sounds as though it is morphine, it has no similarity to morphine at all. In fact the structure of Apomorphine is closer to dopamine itself. Apomorphine does not have any ability to bind what are called opioid receptors to what morphine binds. Therefore, Apomorphine doesn't have any narcotic or opioid effects. Apomorphine is manufactured in such a way that its parent compound is morphine, but because of the significant modifications to the structure, Apomorphine doesn't have any ability to produce what morphine does.

Apomorphine binds very nicely to fats. Therefore it is able to cross the blood brain barrier where it accumulates. Brain concentrations have been known to get 6-8 times higher than in the plasma. Apomorphine is an acidic compound.

Apomorphine cannot be given by mouth; it has to be given in other ways. Therefore it is not to be swallowed because of its metabolism.

HOW IS APOMORPHINE ADMINISTERED?

There are 3 ways in which Apomorphine can be administered.

1. The most common way is by subcutaneous injection. The subcutaneous injection comes in the form of a pen and the doses can be dialed depending on what the individual patient's needs are. The injection works within 4-5 minutes, sometimes slightly longer. It produces very good "on" because, as mentioned above it is a dopamine agonist, which means that it binds directly to the dopamine receptors. Since it can get across the blood brain barrier quickly, as it is injected directly into the blood stream, the action is very quick.
2. Apomorphine can also be injected in a sublingual delivery system. This is a new formulation and has just been approved for use in Canada. The sublingual film comes in various doses. Of course, since it is not an injection, it is not dialed. Therefore, each individual dose comes as a separate strip which has to be opened and then the sublingual film is put under the tongue. Because it has to dissolve under the tongue, it takes longer for this product to work, up to 20-25 minutes.
3. Apomorphine is also available as a pump therapy subcutaneously, although this is not available in Canada. This would be similar to an insulin pump where the medication is delivered under the skin but rather than an injection with a pen, it is subcutaneous pump system.

In addition to this, Apomorphine has been tested in other forms: inhalation, intranasally and rectally. However, these are not currently used therapeutically.

WHO IS A GOOD CANDIDATE FOR APOMORPHINE?

Apomorphine is used only for those patients who have significant "wearing off" periods. These "wearing off" symptoms are those that return when the Levodopa that the patient is taking usually wears off. The symptoms can be both motor, such as stiffness, slowness, tremor, etc., or non-motor, such as anxiety or mood changes. As long as the symptoms are responsive to dopaminergic therapy, the use of Apomorphine would be possible.

Apomorphine is used primarily as an adjunct rescue therapy for patients. It is not used as standard 4-5 times a day administration routinely. If a person is having that degree of "wearing off", other strategies such as adjustment of oral medications have to be done. In fact, to qualify for Apomorphine therapy, patients must have tried all the usual techniques for treatment of severe "wearing off", including addition of medications, such as oral dopamine agonists, enzyme inhibitors, etc. Only when these drugs have been exhausted can Apomorphine be used.

Most of the time, I have looked at Apomorphine as being something that has to be given acutely for a patient who is experiencing significant "wearing off". For example, if a patient is in a chair or lying in bed and has become so stiff and slow that the caregiver or the patient are unable to get them mobilized, then an injection or sublingual administration of Apomorphine would be the way to get them to turn "on". Another use might be when someone has to have a procedure where they can't take anything by mouth, or post-operatively they are unable to swallow, then Apomorphine can be used to continue giving dopaminergic therapy.

WHEN IS APOMORPHINE PRESCRIBED?

I have already described above the types of candidates for whom Apomorphine would be prescribed. Once Apomorphine has been used in our hands in Canada, over the next few years, the domain of eligible candidates will probably expand.

For example, it may be impossible for us to use standard dopaminergic oral therapy, or other therapies mentioned above in many patients. If these patients are unable to tolerate standard oral medications, we may be able to use Apomorphine even earlier rather than waiting for the standard medications to be exhausted. This may also be true in patients already receiving other advanced therapies, such as deep brain stimulation or duodopa pump. In these patients, it may be possible for us to use both those therapies as well as adding Apomorphine for intermittent “wearing off”. Sometimes we would have to reprogram the DBS device, or give booster bolus to the duodopa pump. In those scenarios one can envision an addition of Apomorphine in either way, injectable or sublingual.

WHAT ARE THE ADVANTAGES OF APOMORPHINE?

Apomorphine is the most potent dopamine agonist that is available today outside of Levodopa. The big advantage over Levodopa is that Levodopa takes 30-40 minutes to kick in, whereas the injectable form of Apomorphine works within 5-7 minutes and even the sublingual form is pretty quick. The main advantage of using even the sublingual, even though it takes time, over just giving oral Levodopa for example, is that oral Levodopa, has to travel all the way into the small intestine to be absorbed. If there are any other issues such as delayed gastric emptying, food, protein interaction, then even taking oral Levodopa which can work quickly in 20-30 minutes, will be impeded. Apomorphine, either injected or sublingual, doesn't face these challenges and therefore, those patients that are experiencing “wearing off” because of absorption issues from Levodopa will be great candidates for using Apomorphine.

WHAT ARE THE DISADVANTAGES OF APOMORPHINE?

The main disadvantage of Apomorphine is that it is so potent that you can't simply write a prescription to be dispensed at a pharmacy. Apomorphine dosages, both sublingual and injectable, have to be first titrated in our presence in the outpatient setting. Therefore, for both these drugs, the patient has to be given pre-medication for 2 major side effects that occur and this has to be monitored.

The first symptom is severe nausea and/or vomiting. To avoid this, we prescribe Domperidone up to a week in advance so the patient is pre-medicated with Domperidone before arrival for titration in our clinic.

The second symptom is low blood pressure (orthostatic hypotension). Therefore, blood pressure lying and standing has to be monitored while the titration dose is being tested in front of us. This takes several hours because between each dose of Apomorphine we have to wait at least a couple of hours. Therefore, we start at the lowest dose and then increase as required to determine if the patient is experiencing an appropriate and reasonable “on” after the injection. If the dosages have to be increased 2 or 3 times, it might take a whole day of titration and this is a significant amount of time for the physician, our team, the patient and the caregiver. Therefore, administration of Apomorphine would probably not be done in routine neurological practices in the community because such resources are probably not available. That is why since the use of Apomorphine is resource-intensive, it will most likely only be done in the Movement Disorder Centres. It would not be something I would recommend at all for general medical or neurological practices outside of such centres, unless they have the resources to do what I have mentioned above.

Once the nausea is well-tolerated and if there are no side effects such as lowering of blood pressure, then certainly Apomorphine can be titrated at home as needed on the phone although at the moment we aren't doing this. Therefore, the main disadvantage is the time that must be committed to making sure Apomorphine is used. However, it works quite well and it is worth investing the time if the patient is an appropriate candidate.

DOES APOMORPHINE REPLACE EXISTING PARKINSON'S MEDICATIONS?

Apomorphine is not a replacement for any of the existing medications. However, it is a potent dopamine agonist. It may be possible for patients to be taken off the regular dopamine agonists by mouth if Apomorphine is used. Of course, experience with usage in Canada will determine what profiles we will have overall, because Parkinson's disease is a complex disease. I would say that Apomorphine is an excellent addition to our medical therapeutic, but it is not a replacement.

IS APOMORPHINE AVAILABLE IN CANADA?

Injectable Apomorphine is available in Canada. Sublingual Apomorphine is just becoming available and should be ready for us to use in the near future.

WHAT IS THE COST OF APOMORPHINE? IS IT COVERED UNDER A DRUG PLAN?

Apomorphine is covered for patients over 65 by the exceptional access program, but special forms have to be filled out for this. Therefore it is most likely that Movement Disorder Centres will be using Apomorphine because getting the paperwork done properly is important. As mentioned above, most patients must have tried other standard therapies of Parkinson's disease. Therefore, the EAP will only cover costs when such therapeutics have been exhausted. As far as I know, drug plans do cover Apomorphine but there are so many different types of plans and coverage that it is difficult to answer whether or not universally all drug plans will cover Apomorphine. It would be advisable if the Movement Disorder Centre that you are going to wants to put you on Apomorphine, that special resources be set up through the company as well as through the centre. Also, the insurance company should be asked about coverage if the patient has appropriate coverage for both under and over the age of 65.

Festination and Falling in Parkinson's Disease: My Thoughts and Reflections

When I was 18 months old, my dad was diagnosed with Parkinson's disease (PD). This has allowed me to witness the progression of his symptoms since I have grown up alongside it. That being said, it's important to note that I am certainly no expert on the variety of symptoms that PD patients can express, nor the equivalent neurology. However, I can draw from my detailed and thorough understanding of my father's experiences in the hopes that some of my thoughts and reflections can be of value to others living with PD. My goal here is to discuss my father's experiences, with falling and festination, patterns that I have noticed. Hopefully some methods of prevention can be applicable for other people battling PD.

I think it is good to note right away that my dad was very active and in good shape throughout his life before PD. His fitness level prior to diagnosis was extremely valuable in maintaining his mobility following his diagnosis. Furthermore, he is still able to walk outdoors every day after almost 20 years with the disease. This is to emphasize how important it is for people with PD, much like everyone else, to be physically active and remain so to the best of their ability.

Sometimes when we are walking the dog, my dad begins to slow down, this is one of the main predictors of a festination beginning in his gait. Festination occurs when a person's walking stride, also referred to as gait, begins to shorten in length, the steps get smaller and the strides are weaker. For my dad, this becomes a shuffle where his feet are moving forward but are barely leaving the ground. As the steps shorten and dad attempts to keep his momentum moving forward, a time comes when his feet don't take a step at all and his upper body continues to move forward but his legs have stopped, causing him to fall over. Luckily, when my dad experiences festination, it is a gradual onset and therefore his falls are predictable and preventable. However, an important point to make is that for some people with PD, festination might be more common than just when they are slow or are slowing down. The stiffness in the legs and the festination could be present for most of the day and therefore the chance of falling could be higher.

More importantly, I have noticed a few strategies that really help my dad extend his stride. When his gait begins to shorten, we know it's time to pick the most direct path home so we can get back safely without getting stuck. The biggest thing we do in this scenario is use rhythm and momentum as my dad begins to shuffle. I walk beside him saying "left right left right" and he matches his left and right steps with these words, while matching his walking speed to the tempo of my marching chant. This allows a rhythm to be made and momentum can slowly be built up to the point where he is almost doing a shuffle/jog. The key is to keep the rhythm and maintain it until we reach home. If we lose the rhythm and the momentum stops, sometimes to get going again is incredibly difficult.

At home we use some other strategies. One of my dad's ideas was to put small pieces of tape along the hardwood floor so that when he was struggling to take steps he had small markers, almost like a track, to follow and to aim for with his feet to prevent his stride from naturally getting shorter. As time has progressed my dad's ability to reach a destination without some support has decreased. This is where we introduced a walker. The walker helps tremendously in giving my dad the ability to walk on his own and provides support for his upper body. By doing so, he can maintain a decent posture and stop himself from falling forwards if his feet stop moving. The walker is also an excellent tool to go for walks outside the house. However my dad does not want to use a walker outside. Instead he uses a cane. This is not as reliable as a walker but it is still very beneficial to his stability. I also want to emphasize the knees. Personally, I feel as though this is where the main problem resides during festination. Being able to do 'high knees' as an exercise, or likewise walking up and down a staircase, is incredibly beneficial. This helps in maintaining fluidity in the knee and can subsequently help someone with PD walk in general. Focusing on lifting your knees while walking provides the momentum to move forward and can hopefully allow you to walk more effectively. Remember always have a walker or someone watching when doing high knees to keep your balance. Also, if you are going up and down the stairs, have solid railings on both sides for support and grab if you get stuck.

Interestingly enough, my dad's most common falls are not from a typical festination, nor are they from losing balance. For my dad, it is what my mother and I like to call 'micro-freezes.' Now this is mostly synonymous with the term 'Freezing of Gait' or FoG, where for a brief moment someone with PD is unable to take a first step, or while in the middle of walking can all of a sudden not move. Studies have continually shown that the prominent cause of FoG seems to be when people are initiating a step forward, changing direction, going through doorways and are rushed or stressed.

Anke Snijders and colleagues found in 2008 that the most common description used for FoG seemed to be “a feeling of being glued to the floor.” It is also important to consider that PD patients may sometimes have poor perception, so if something is visually misinterpreted or perceived incorrectly, this can also lead to FoG. Division of attention is important as well. FoG can arise quite frequently as I have seen in my dad when he is walking and trying to do something else at the same time. For example, once when my dad was walking, he took a handkerchief out of his pocket to blow his nose. This split of attention between blowing his nose and walking caused his feet to abruptly stop and he took a tumble. The reason my mother and I have used the word ‘micro-freeze’ is because these falls almost always occur to my dad when he experiences dyskinesia (excessive movement from too much medication getting to the brain). We will be walking and then suddenly his legs stop and he hits the ground hard. The reason we don’t use FoG to describe my dad’s case is because the context of medication is usually that a person does not have enough dopamine and an increase in medication will decrease bouts of FoG. My dad seems to demonstrate the opposite. Remember this is merely an observation of a consistent trend which I have seen in dad over many years now, but is certainly one that could use some research. If you would like to learn more about FoG, I highly recommend starting with Dr. Rebecca Gilbert’s recent blog where she does a comprehensive review of the condition. The link to her blog on the American Parkinson Disease Association’s website is here: <https://www.apdaparkinson.org/article/freezing-gait-and-parkinsons-disease/>

Therefore, in relation to falling, it is important to familiarize yourself with the scenarios in which you are most likely to fall. It is one thing to be frozen and another to struggle to walk, but it is worse to physically hurt yourself because of these symptoms. Even for the most unpredictable scenarios such as FoG, try to find physical factors or trends that can suggest a fall might be likely to happen. For example, with my dad and his dubbed micro-freezes, I know they are almost always during dyskinesia, so when this is present I will always walk closely beside him and even interlock my arm with his so that I am in a position to stop him from falling or to at least minimize the impact. For a person with PD, learning how to properly and instinctively reduce the force of impact during a fall is very important. This may be more applicable to those who have an early onset diagnosis. My dad has learned to break his fall by doing a pretty epic barrel roll. Remember to protect your head at all times- this is the last thing you want making contact with the ground. Be wary of your hands, wrists and knees as they are primary locations of impact. A barrel roll certainly will not work for everyone but finding and mastering the best way to break a fall for yourself can be key to preventing debilitating physical injuries, and ultimately to maintaining an enjoyable life.



Simon Hawke is from Vancouver, B.C. and is currently in his 2nd year at Western University enrolled in the Neuroscience Program.

Ten Tips to put the Freeze on Freezing!

1. Try another movement – raise an arm, touch your head, point to the ceiling; then re-start.
2. Change direction - if you can’t move forward, try stepping sideways first, and then go forward.
3. Carry a laser pointer in your pocket - when you freeze, shine the laser in front of your foot and step on the light. This visual cue can help you re-start.
4. Visualize an object on the ground in front of you and try to step over it.
5. Wear a metronome on your belt or carry a small one in your pocket. Turn it on and the external beat can help you re-start.
6. Try humming a song and time your re-start with the beat of the music.
7. Count “1-2-3-go” and then step forward.
8. Shift your weight from side to side to help initiate taking a step.
9. March in place a few times and then step forward.
10. Don’t fight the freeze by trying harder to step forward – shift your attention from moving the legs to moving the arms. Then resume walking forward.

While these methods can be helpful to get out of a freeze already underway, physical therapy techniques that incorporate these types of cueing strategies are utilized to reduce freezing of gait overall. Rhythmic auditory cueing is one such technique which utilizes rhythm and music to improve gait in PD and other neurologic diseases.

Taken from American Parkinson Disease Association’s website:

<https://www.apdaparkinson.org/article/freezing-gait-and-parkinsons-disease/>

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The PSSO Parkinson's Choir

Written by Sophia Christopher

Did you know that singing in a choir can have multiple health benefits – especially for individuals who are experiencing Parkinson's disease? Parkinson Society Southwestern Ontario (PSSO) has piloted a new choir designed specifically to address and meet the needs of individuals experiencing Parkinson's disease. The Parkinson's choir is a fun and engaging way to meet functional speech-related and psychosocial goals.

WHAT DOES THE CHOIR LOOK LIKE?

The PSSO Parkinson's Choir is a 12-week virtual program led by a music therapist trained in neurologic rehabilitation. The choir is designed to exercise and strengthen an individual's respiratory strength. Over the duration of an hour, individuals will participate in vocal and respiratory exercises, as well as sing client-preferred and client-chosen songs. Some interventions include:

Vocal Intonation Therapy (VIT) is a neurologic music therapy intervention. It is the use of vocal exercises to train, maintain, develop and rehabilitate aspects of vocal control because of neurological, physiological or functional abnormalities of the voice apparatus. This includes aspects of vocal control such as inflection, pitch, breath control, timbre and dynamics. Many VIT exercises are similar practice to choir warmups and exercises and are targeted specifically for those experiencing a neurologic condition.

Therapeutic Singing (TS) refers to the more generalized use of singing activities for a variety of therapeutic purposes. In the case of a choir group, this technique can synthesize a range of specific speech, language, respiratory control and vital capacity goal areas into an integrated therapeutic experience. Therapeutic singing can also be utilized as a physical exercise technique to address global vocal and respiratory strengthening and endurance. Because therapeutic singing allows direct engagement in musical creation, it can be a success-oriented technique, creating motivation and a positive experience.

In addition to the benefits of singing on vocal control and breath support, singing has direct psychological benefits, including both intra-personal growth and development of individual identity. Music psychosocial training and counselling incorporate the use of musical performance to address issues of mood control, affective expression, cognitive coherence and appropriate social interaction to facilitate psychosocial functions.



*Sophia Christopher holds a Bachelor degree in Music Therapy and a Master of Arts degree in Music and Health Sciences Collaborating in the Neuroscience Program. She is an accredited music therapist (*MTA) through the Canadian Association of Music Therapists, and received the title of a Registered Psychotherapist through the College of Registered Psychotherapists of Ontario. Sophia completed further training with the Robert F. Unkefer Academy for Neurologic Music Therapy to become a Neurologic Music Therapy Fellow. Specializing in neurologic rehabilitation, Sophia incorporates musical and non-musical activities to achieve motor, speech and cognitive goals, through the use of evidence-based techniques. Sophia has had the opportunity to collaborate internationally with various music therapists and research teams. As a music therapist, Sophia has a passion for helping individuals of all abilities reach their fullest potential.*

BECOME A HERO OF HOPE

By becoming a monthly donor, you become a Hero of Hope! Your monthly gift ensures sustainability of programs and services as you invest in the lives of people living with Parkinson's in our community.

For more information, contact Jessica Halls at jessica.halls@parkinsonsociety.ca or by calling 1-888-851-7376.



HOW DOES IT WORK?

VOCAL SUPPORT AND REHABILITATION

A significant amount of research has examined the use of singing to treat speech-motor abnormalities associated with various neurological conditions due to the biological similarities between singing and speaking (Ozdemir et al., 2006; Wan, 2010). Because singing and speaking use the same vocal mechanisms to produce sound, singing can be an effective tool for addressing specific aspects of vocal control in therapy. Singing directly effects respiration, phonation, articulation and response, and respiratory muscle strength (Natke et al., 2003; Tonkinson, 1994; Wiens et al. 1999). Numerous studies have reported positive affects resulting from the use of vocal exercises and training in clients experiencing Parkinson's disease (DeSteward et al., 2003; Haneishi, 2001; Ramig et al., 1994; Tautscher-Basnet et al., 2006). The use of structured, purposeful singing, in combination with other vocal therapy techniques, has been shown to be an effective therapeutic tool.

PSYCHOLOGICAL BENEFITS OF SINGING

Many studies highlight the inherent richness of the musical experience of singing, and reinforce the concept that therapeutic singing can reach out to individuals on social and emotional levels to increase their engagement in therapy and improve their quality of life. Hodges (1996) and Hodges and Sebald (2011) have studied how music can evoke and alter emotional reactions. It has been well documented that music can positively affect mood through the release of dopamine (Evers and Suhr, 2000; Hodges, 2010; Menon and Levitin, 2005) as well as induce pleasure and emotional arousal (Salimpoor et al., 2009; Kruetz et al., 2008). Welch et al., state that "Group singing is one of the most positive forms of human activity, supporting physical, mental and social health, as well as individual development" (2010).

SOCIAL INCLUSION AND GROUP COHESION

A growing body of literature supports the health and wellness benefits of group singing. For example, singing in a group setting can improve social skills and foster a greater awareness for others (Clift et al., 2009a, Clift et al., 2009b; Cox et al, 2010; Cuypers et al., 2011). Goldberg et al. (1988) found that music therapy groups produced more therapeutic interaction and emotional responses when compared to verbal therapy. Research has demonstrated that by providing experiences of similarities, members begin to establish a sense of community, while feeling supported and accepted.

Through the PSSO Parkinson's Choir, individuals will be able to participate in a fun and engaging activity while feeling supported by other group members and meeting functional goals. This group will provide a safe environment in which participants are able to take social risks, experiment in alternative interactions and improve quality of life.

For more information or to register, contact **Lisa Nixon** at info@parkinsonsociety.ca.



**A GIFT
TODAY IS
HOPE FOR
TOMORROW...**

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 that others that come after you have the opportunity to fight well.

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.

Call 1-888-851-7376 for more information on leaving your legacy.

Is it Time for a Nursing Home?

Written by Christine Kliever

For those of you who are asking yourselves this question, did you know that for some of the more coveted long-term care homes, your time on the waitlist could be five to seven years? That's right – YEARS. If you are in a time-sensitive situation, there are beds available fairly quickly for emergency situations. These tend to be the long-term care homes with more basic amenities. Long-Term Care Homes is the formal title for Nursing Homes, as they do provide so much more than nursing care.

The very first step is to be registered with your local LHIN (Local Health Integration Network). This world can come across as alphabet soup, so I will try to clarify who is who! In May 2017, the LHIN took over the management of what had previously been known as CCAC, the Community Care Access Centre. If you have been dealing with CCAC already, then don't worry – the people and phone numbers remained exactly the same.

Every long-term care home works with the LHIN in managing the waitlists, but you cannot get on the waitlist for a home any other way but through registering with the LHIN.

I AM 90 YEARS OLD, WHY DON'T I QUALIFY FOR LONG-TERM CARE?

This really happened to my 90-year-old Grandma. She was still in her own apartment and managing fairly well. Although she got tired more easily, she was still independent and able to do most things for herself and thus did not qualify for a long-term care facility.

It is important to remember that although your age is considered for the Care Coordinators, being old does not make you automatically eligible. There are a number of supports including getting help at home, moving to a place with some supports or moving to a retirement home.

.....

Christine Kliever grew up just outside of Rockwood, Ontario. She obtained her Bachelor of Arts with a Certificate of Social Work from University of Waterloo and has over 25 years of experience working within the Waterloo region health and social services community. She strongly believes in giving back to her community and has volunteered for the Alzheimer Society, Hacking Health, Parkinson Society Southwestern Ontario and the Belmont Bestival.



Three of Christine's grandparents required the help of family, friends, home care, retirement and long-term care before they passed away, and she currently supports her mother-in-law whose rapidly changing situation has taken her from her home to a retirement home to long-term care in less than two years. She understands clearly the less-than-perfect options that currently exist to support individuals and families.

HOW DO I REGISTER?

- Your doctor can refer you
- Call them at 519-748-2222
- Fill out the online form at: <https://healthcareathome.ca/www/en/Contact-Us>
- If you are in hospital, a LHIN Discharge Planner will help you there

WHAT HAPPENS WHEN I REGISTER?

- A Care Coordinator comes to your home
- An interview and an assessment are conducted
- Your family is encouraged to attend
- The Case Coordinator provides a list of all the Long-Term Care homes in the region and you choose up to five locations.

The Care Coordinator's job is to ensure you get a placement in a long-term care facility. They are not allowed to advocate for one home over another. They can give you some information, such as the waitlist (<https://www.wwhealthline.ca/libraryContent.aspx?id=20564>) for each home, to help you with your decision. You need to visit the homes, do the research and figure out which ones match your needs and preferences.

You might be interested in this CBC Kitchener-Waterloo news article (<https://www.cbc.ca/news/canada/kitchener-waterloo/ltc-reunification-long-term-care-fife-1.4546129>) about MPP Catherine Fife's advocacy on behalf of an elderly couple who have been split apart because of the guidelines that govern both the LHIN and long-term care providers.

What is Facial Masking in Parkinson's Disease?

Written by Sarah Awde

Also referred to as "masked facies" or "hypomimia", facial masking is a common symptom of Parkinson's resulting in the reduced ability to show facial expression. However, not all people with Parkinson's experience the same symptoms, or to the same severity. When people with PARKINSON'S have a mask-like expression, their face has less range of movement and appears less animated.

We know that Parkinson's is a disease of "low amplitude". Everything can become diminished, from vocal loudness, to length of stride to range of arm swing. The lack of dopamine can also result in the facial muscles becoming "reduced" in their range of movement. In addition, those with Parkinson's may be unaware of this and may FEEL as if they are being animated in their facial expression. Are you noticing a pattern here? It's the same faulty feedback loop that results in individuals with Parkinson's feeling that they are speaking at a normal loudness level!

Did you know that there are 43 muscles in the face? Normally they work seamlessly and without any real conscious effort on our part to relay how we are feeling. Humans naturally supplement verbal speech with an endless range of smiles, frowns, grimaces, eyebrow raises ... the list goes on. Some expressions are large and animated; others are subtle but convey much more than words ever can. But they all contribute to our communication partner how we are really feeling.

When an individual with Parkinson's loses the ability to "communicate" via facial expression, it can have catastrophic results. Others may interpret this lack of facial expression as disinterest or even apathy or anger, resulting in a negative communication experience. Family and friends, who don't understand the CAUSE of facial masking may (even subconsciously) feel unwilling to interact with the individual with Parkinson's, which can lead to social withdrawal and even depression.

Understanding the CAUSE of facial masking, having open conversations with loved ones about this Parkinson's symptom and knowing how to compensate for the reduced facial muscle movements can greatly improve social interactions and one's quality of life.

Daily Parkinson's specific speech/voice exercises as well as targeted facial exercises should be done regularly to improve the symptoms of facial masking.

Have you experienced symptoms of facial masking? If so, how has it affected you socially?



Sarah Awde is an Ontario registered Speech Language Pathologist with over 16 years experience working with adults with every manner of communication and swallowing impairment. She currently runs a private practice called Get LOUD! Therapy, working exclusively with individuals with Parkinson's disease. Sarah is thrilled to partner with PSSO to offer online LOUDER CLEARER PD voice exercise classes.



VOLUNTEER TODAY!

With your help we can do so much more for people living with Parkinson's

Interested in helping with your local walk? We're looking for volunteers to join in our efforts!

Contact Jessica Halls at Jessica.halls@parkinsonsociety.ca or 1-888-851-7376 to find out how you can help.



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- *Parkinson Society Southwestern Ontario and our services*
- *Parkinson's and Parkinson's programs*
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- *And more ...*

My Experience With Anxiety It's Not All in Your Head...

Written by Dr. Soania Mathur

My thoughts are racing, my mouth is dry and I can feel my heart pounding in my chest. Sometimes these symptoms come with a fleeting feeling of dread, the kind I have experienced when I would lose sight of my little one in a crowd but soon spot them inches away. Or it may be part of a prolonged night of worry as I lie there illogically concerned about a countless number of health issues that could potentially plague my family. Disturbing, negative thoughts that take over my peace of mind, sabotaging my need for an often unattainable night of rest. These episodes are yet part of another unwelcome consequence of this disease that I have been living with for over two decades. Yes, feelings of anxiety are now part of my Parkinson's experience.

Now granted, I don't fit the criteria for a diagnosis of clinical anxiety. My episodes are few and far between at this time, and frequency and severity are an important part of the strict criteria that must be met prior to such a diagnosis. Moreover, in my case, my feelings of anxiety have not interfered with my functioning. However, to be honest, when they do occur, they definitely impact my quality of life.

I was never an anxious type of individual. Not that I was immune to stress of course, but my response was not one of anxiety. During my medical career for instance, there were emergencies that would trigger a release of adrenaline, but my approach remained focused and logical. Those episodes were not accompanied by racing thoughts, and a feeling of doom or fear. Instead the adrenaline would carry me through as I tackled whatever issue was at hand.

And that is still my response to most situations. However now, occasionally I will feel an overwhelming sense of anxiety. Often not related to any particular circumstance, these discreet episodes come out of nowhere, insidious and usually only debilitating for a few brief moments. The exception is at night when these episodes tend to last longer as the lack of distraction and hours of darkness ahead of me often prolong the feeling.

Although it is difficult to pinpoint an exact cause, there is definitely some correlation with my disease burden. If I am lacking in sleep or have skipped my exercise routine, a general lapse in self-care, along with all my other motor and non-motor symptoms, my mood also suffers. In most cases I have learned to tackle these feelings. By focusing on my breathing and through an internal dialogue to break the onslaught of frightening, negative thoughts, I am able to pull myself out of that spiral of anxiety. Thankfully.

But others are not so lucky. Many in our community are paralyzed with anxiety and/or depression, isolating themselves and living a severely compromised quality of life. Parkinson's is insidious and global in its nature, affecting us not only as a motor disorder but other body systems, mentally and emotionally as well. Mood disorders, depression and anxiety are part of the nonmotor complications of this disease and are particularly impactful on quality of life. Approximately 30-50% of people living with Parkinson's disease will experience anxiety at some point during the course of their disease and approximately the same number will suffer from depression. In many individuals these two will coexist. That is compared to 5-10% in the general population.

We are not talking about difficulty coping with this disease or worrying about what the future will bring when you are facing an incurable, progressive neurodegenerative disease. Those concerns and worries are expected and a natural part of the journey with any chronic illness. But when your feelings of anxiety do not resolve themselves and begin to affect your functioning, restrict your activities and when you have symptoms more often than not, then you must take the next step and seek medical attention. Mood disorders in Parkinson's disease are treatable, often with good results, thereby changing your life and disease experience.

Why do so many still languish with untreated mood disorders? Part of the reason is the unnecessary stigma associated with mental issues, the fear of being thought of as weak and unable to cope, of being judged as succumbing to the challenges of this diagnosis instead of being able to push forward past the obstacles. Well, let me ask you this question. If you broke your arm, would you not seek treatment? Would you not get the medical attention you needed to heal your bones? Mood disorders are the same thing. They are biologically based and are medical conditions like any other illness or injury. They are not a reflection of weakness or an inability to cope. They are a complication of Parkinson's that requires your awareness and management by your healthcare team.

That is part of my reason for doing this blog - to get this simple message across.

Anxiety and depression are nothing to be ashamed of. There is a biological and medical reason for you to be feeling the way you feel and there are treatments that can help you feel better. You must be proactive in taking care of both your physical and mental health.

As a community, we need to overcome the stigma, normalize discussion about mental health issues and encourage those who are affected to seek the help that they so greatly need.

As I finish this blog, the sun has come out, reflecting off the new snow that fell during the blustery night. It buoys my optimism and hope for the future. There is no sign of my anxiety at the moment, but I know that if I am no longer able to see the beauty of days like this, if my thoughts are mired in worry and negativity, that I will not hesitate to ask for the help that I know exists. I only have to take that first step and ask.



Dr. Soania Mathur is a family physician who had to resign her practice following a diagnosis of Young Onset Parkinson's Disease at age 27. Dr. Mathur now dedicates her time to patient education, writing and Parkinson's advocacy. For further information, go to www.unshakeablemd.com



Non-Death Losses Associated with Parkinson's Disease

Written by Melissa Chamberlain

Many individuals hear the word grief and associate it with death. However, over the course of our lives, we also deal with a number of non-death losses, that also illicit grief reactions. When an individual is diagnosed with Parkinson's disease, there are a number of losses for the individual, including loss of health, loss of imagined future, loss of independence, among others. Whether it is a new diagnosis, or a progression in symptoms, both have losses and challenges associated with them.

There are several different challenges present for care partners and family. Some of those challenges and losses may include transitioning into a care partner role, relationship issues, loss of imagined future, as well as anticipatory or ambiguous loss.

Anticipatory loss is grief that occurs in anticipation of something. For example, grieving the progression of an illness, or a death before it actually occurs. Ambiguous loss is when an individual is grieving a loved one that is physically present but may not psychologically be the same person they used to know. It is also grief associated with someone who may be psychologically present in our minds, but is physically gone, i.e., someone who is missing, or a long distance away. These losses and challenges can be very complex, and difficult for not only the person with Parkinson's, but also for family and carepartners.

If you or a loved one are struggling with any of the above challenges, situations or losses, counselling may be of benefit to you. Parkinson Society Southwestern Ontario, in partnership with King's University College, is now offering free short-term counselling with a social work student, in-person at the PSSO office in London, via zoom, or over the phone.

If you would like to know more or schedule a meeting, please email counselling@parkinsonsociety.ca or call the PSSO office at 1-888-851-7376.



Melissa Chamberlain is a 4th year student in the King's Western University Social Work program. She is currently doing her placement at Parkinson Society Southwestern Ontario.

Parkinson's Disease and Night Time Issues

Written by Ria Singla

Sleep is vital for our body to repair and heal itself. It is no surprise then that for those suffering from chronic disease, being well rested and having energy is essential. However, approximately 64% of individuals suffering from Parkinson's disease suffer from sleep disorders. Some of these issues include insomnia, daytime drowsiness, sleep apnea, vivid dreams, tremor and restlessness. They often increase in frequency as the disease progresses.

WHAT CAUSES SLEEP ISSUES IN PARKINSON'S DISEASE PATIENTS?

Parkinson's disease patients commonly suffer from sleep disorders because of the symptoms of the disease itself, or because of side effects of the medications they take to manage the disease. For example, motor symptoms can make it difficult for patients to adjust to a comfortable sleeping position. Medications such as dopamine agonists and COMT inhibitors, both of which are common treatments for Parkinson's disease, can lead to sudden sleep onset and sleep disturbances.

COMMON SLEEP DISORDERS AFFECTING THOSE WITH PARKINSON'S DISEASE

- 1) REM (Rapid Eye Movement) Sleep Behaviour Disorder. This disorder is characterized by violent motor movements where individuals act out their dreams. The disorder is commonly caused by issues in regions of the brain that control REM sleep. For patients suffering from REM sleep behaviour disorder, having a secure bedroom is essential to maintain safety.
- 2) Restless legs syndrome. This disorder is characterized by an urge to frequently move legs because of uncomfortable sensations in the legs. Mild restless legs syndrome can commonly be managed by lifestyle changes.
- 3) Insomnia. This is the most common sleep disorder in Parkinson's disease patients. Patients suffering from insomnia experience difficulties in falling asleep or maintaining sleep.

MANAGING SLEEP ISSUES

There are various common lifestyle strategies which patients with Parkinson's disease can try that may help improve their sleep. These include:

- Avoiding caffeine before bed. Being a stimulant and having long-lasting effects, caffeine can make it difficult to fall asleep, and can contribute to restless sleep.
- Relaxing before going to bed. Having a calm mind may allow patients to fall asleep easier and faster. This can be accomplished in many ways, including reading, watching television or listening to music before heading to sleep.
- Reducing disturbances in the bedroom. Parkinson's disease patients should avoid light by turning off the television before sleeping and covering the windows with curtains. An eye mask and ear plugs may also help.
- Developing a regular routine of sleeping at a consistent time daily.
- Patients should consult their doctor for over-the-counter or prescription sleep medications. The doctor can also adjust treatment or dosages of medications that patients are taking to manage Parkinson's disease symptoms if they appear to be interfering with their sleep.

NOTE: A recording of Dr. Mary Jenkins' webinar – Sleep Tight – Night Time Issues in Parkinson's from November 13, 2020 is available by going to <https://parkinsonsociety.ca/videos-and-audios/>

Ria Singla is a fourth year student in the medical science program at Western University. She is very passionate about helping others and making a positive difference in the community!



Accessing Your Specialist During The COVID-19 Pandemic

Written by Racheal Madray

The worldwide coronavirus pandemic has transformed lifestyles for many people. Although social distancing during the pandemic is essential, it may feel isolating and disrupt access to your physician. This may ultimately affect the management of your Parkinson's disease (PD) symptoms. How can you access your specialist during the pandemic?

The use of telemedicine has become increasingly common since the pandemic began. This includes setting up virtual appointments with your doctor through platforms including Zoom or Skype. In fact, because of long wait times, this pandemic has been the first instance where some individuals have been able to see a movement disorders specialist. If your symptoms are stable, setting up virtual appointments with your doctor can allow your doctor to meet with you, discuss the details of the medications you are taking, and adjust your dosages accordingly. Additionally, it allows your doctor to see how you function in your home and it provides flexibility in the scheduling of your appointments. Thus, you may want to ask your movement disorders specialist or primary care physician to set up virtual meetings to discuss changes in your symptoms or about your medication regimen. During this time, you may also talk to your doctor about setting up automatic refills for your medication in the upcoming months, and setting up delivery of your medications to your house from your local pharmacy.

You may also use this time to discuss how your PD medications may interact with over-the-counter (OTC) medications. For example, some individuals who have been infected with coronavirus may rely on OTC medications, including cough suppressants and cold/flu medications. Some of the ingredients in these medications are not meant to be taken with PD medication. Thus, telemedicine will allow you the flexibility to stay in touch with your specialist and remain informed about your condition and treatment options.

You may experience technical or Internet difficulties while setting up video calls with your specialist. Consider asking a family member who is fluent with technology to help with any confusion or problems that may arise. An alternative option is to set up asynchronous meetings with your doctor. For example, you may take videos of yourself either discussing or displaying changes in your symptoms. Your specialist may respond with a video at a different time, and thus maintain communication with you. Other options for staying connected include setting up phone calls with your movement disorders specialist or exchanging texts/emails with your specialist.

If you would like to meet with your specialist because of a change in your symptoms, you may want to call your doctor's office and request an appointment in person. They may have special protocols in place for ensuring your safety during a visit.

It is important to monitor your symptoms and speak to your doctor about the different ways you may keep in touch. Remember to keep a regular inventory of your medications and make a list of your doctors and their contact information to refer to if needed at a later time.

According to Rachel Dolhun, a movement disorders specialist and the vice-president of medical communications at the New York-based Michael J. Fox Foundation, "there are so many ways now that we can connect with other people and be part of a community, even though we are physically apart ... technology offers us so many routes to be together while socially isolating." Dolhun highlights that virtual chats and phone calls are a viable option to stay connected. Furthermore, surveys collected by the Michael J. Fox Foundation have shown that many patients with Parkinson's disease have reported that they are satisfied with the telemedicine interactions with their doctors. In fact, research has shown that virtual appointments from a physician are equally as effective as appointments in person. Overall, there are many ways to stay connected during this pandemic.

Despite our need to remain socially distant, communicating about these options with your specialist will allow you to remain connected.

Racheal Madray is a student at Western University completing her final year of her undergraduate degree in Neuroscience and Pharmacology.





**WALK THE BLOCK
FOR PARKINSON'S**

THANK YOU for raising over \$266,000!



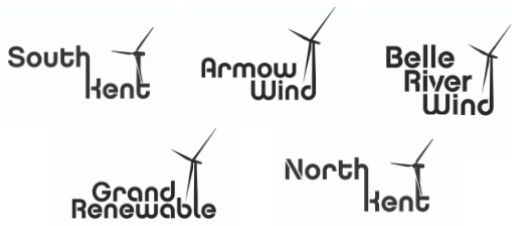
TOP WALKERS

1. Clare Poechman \$10,206
2. Christine Scheer \$7,608
3. Mary Vernon..... \$5,451
4. Carolyn Young..... \$5,071
5. Scott Dunbar \$5,068
6. Stuart Selby..... \$5,007
7. Robert Ecclestone \$4,979
8. Don Sarasas..... \$3,801
9. Grant Bourner..... \$3,331
10. Michelle Napper..... \$3,204

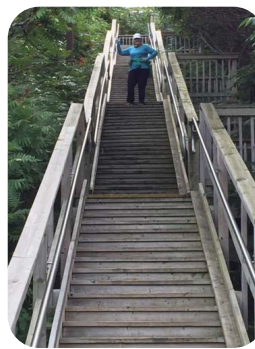
This year, we invited you to walk, just a little differently and we're so thankful that you did! Pictures and videos from all over showed that you took on this challenge and made it your own! Walk-It became Walk the Block and hundreds of you worked hard over the summer to raise support and awareness for Parkinson's! We hope that this year will be different and we are already planning what 2021 will look like! At the end of it all, what matters is that we worked together to spread awareness and hope for people with Parkinson's across Southwestern Ontario. We are so grateful – thank you!



2020 WALK The Block for Parkinson's Sponsors



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Thank You!

A Helping Hand through the Pandemic

Launched on May 19, 2020, the Emergency Community Support Fund (ECSF) was a \$350M investment from the Government of Canada to support charities and non-profit organizations serving vulnerable populations as they manage the impacts of COVID-19. PSSO was fortunate to be the recipient of ECSF grants to maintain our programs and services during a very challenging period.

PSSO is grateful to for the support and assistance of the Government of Canada, as well as many of the local Community Foundations and United Way/Centraide organizations in our communities (listed below). They have provided financial support to PSSO, our support groups, webinars, educational programming and staff through the pandemic period.

- Chatham Kent Community Foundation**
- Dufferin (Orangeville) Community Foundation**
- Grand Bend Community Foundation**
- London Community Foundation**
- United Way Bruce Grey**
- United Way Sarnia-Lambton**
- United Way Waterloo Region Communities**
- United Way Centraide Windsor-Essex County**

Volunteer Profile - Richelle Hirlehey

When Richelle Hirlehey's father was diagnosed with Parkinson's six years ago, she wanted to learn more. As she learned and understood, she realized she wanted to give back to the organization that supported both her father and his family. Richelle has now been volunteering and supporting Parkinson Society Southwestern Ontario (PSSO) for over three years.

Her first volunteer experience was with the Hair Affair committee, helping to organize and oversee the event. She then moved on to join the Walk-It for Parkinson's committee in 2019 and was thrilled with both events to have her partner Doug, daughter Ella, step-daughter Kirsten and step-son Dylan, join her on her volunteer journey.



Richelle with her walk team.

In 2019, Richelle was the committee chair for the annual WALK-IT for Parkinson's held at Springbank Park in London, where she, in her words, "worked with a small but incredible group of volunteers and Parkinson's team members." And as we all know, 2020 brought changes. The annual walk became a virtual event, renamed "WALK THE BLOCK for Parkinson's." Richelle took on the role of stewardship on the Regional Committee and assisted with marketing and many aspects of planning for this new and creative way of supporting the organization. "Community participation and support were impressive," Richelle states. "We worked with online donations, the sponsors continued with their support and friends and family got involved. Walking the block gave people flexibility because they were able to walk through their own neighbourhood when it was convenient for them. Some chose conservation areas or different routes, but regardless of where participants chose to walk, the pictures taken during these walks shared the excitement and dedication to the event just as much as in previous years. The compassion and care of the community were clear."

When Richelle isn't volunteering for PSSO, she holds a busy schedule as a full-time kindergarten teacher with the Thames Valley District School Board. She enjoys a part-time role as the assistant director for Dance Extreme, educating and inspiring children and youth in both learning the basics of dance and supporting their achievements through the competitive dance program. Richelle's self-care routine includes yoga, reading and plenty of family time, including nature walks and outdoor activities. The entire Hirlehey/Maczko family has also shared time together, participating in the "Meals from the Heart" dinner program at Ronald McDonald House.

Richelle continues to volunteer with PSSO because of the powerful connection with others. "Seeing everyone come together and support each other is so meaningful and empowering. Everyone is so giving and overall, it's a very family-oriented environment, which is important to me. It makes my heart feel good, and the connection with others becomes an informal type of support group for all of us. I have so many gifts in my life and an incredible family, and to volunteer here at PSSO is a way to be involved and give back to my community."

Richelle says she will definitely continue to stay involved and is looking forward to supporting in the new and creative ways we now need and to help where she can. One lesson she's learned from the events of the past few months is that it has forced many of us to slow down. As a result, we see that slowing down isn't such a bad thing. It allows us to spend more time with those who matter, help where we can and celebrate all that we truly have.

In Memoriam

We offer our sympathy to the families whose loved ones have passed away between July 1, 2020 and December 31, 2020.

George Aberdein
Helen Ahrens
Brenda Anderson
Lonna Arnold
Marie Ashton
Edwin Balm
Bill Barber
Steve Barcic
Diane Barrett
William Blonde
Helen Boogemans
Bob Bourque
Robert Boyce
Karl Brefka
Shirley Buckborough
Mary Jane Bunning
Johanna Burgers
William Burnett
Elda Butler
Muriel Butts
Tony Carrillo
Herbert Chamberlain
Jerry Charland
John Chinn
Sarah Clark
James Coleman
Jacqueline Coll
Shirley Colledge
Robert Cornelius
David Cox
Melanie Craig
Bert Custance

Violet Dalanghe
Roger Dallaire
Richard Damphousse
Theresa Daragon
Robert Davis
Jacob De Vries
George DeBlock
Emma Del Papa
Leroy Denomme
Otto Deutsch
Egidio Didone
Hazel Elliott
Ingrid Enders
Marilyn Evans
Matthew Feeney
Margaret Ferguson
Louis Flannigan
Ralph Franklin
Bob Fulton
John Gagnon
Warren Gear
Raymond Gladwell
Hugh Gordon
Douglas Gough
Martha Grace
Mary Jane Grastaitis
Michael Gregory
Shirley Gunn
Barbara Harcourt
Robert Hawkins
Donna Hayes
Joseph Hiel

George Highgate
Wendy Hill
Bruno Hoffman
Jim Hopkins
Frances Horgan
Jean Mae Hudson
Harold Hudson
Ferne Hutchings
Michael Ireland
James Irwin
Ferne Jameson-Pell
Robert Jasper
Leonard Jenkins
Richard Jennings
Charles Johnson
Joananne Johnston
Prem Kapur
Young-Sook Kim
Don King
Kathleen Kot
Bruce Kriter
Ted Lagoda
Michel Lamadeleine
Kathleen Langlois
Larry Lauzon
Charles Leboeuf
Clare Lehman
Janet Levack
Joseph Lewicki
Robert Longworth
William Lucassen
Susan McCann

William McDade
Jane McIntyre
Ivan Milkovich
Mary Millerson
Helen Moloy
Ines Morelli
Jean Munday
Jim Mutsaers
Margaret Nichols
Fred Nicholson
Odette O'Hara
Adriana Olsthoorn
Vera Orr
Douglas Ouellette
Gordon Overbaugh
Joseph Partito
Meta Paterson
Nancy Peltier
Edward Phibbs
James Piggott
Willard Price
Sherrie Rastel
Gerald Rhody
Terry Richardson
William Robinson
Jane Rutledge
Elena Saffran
Dennis Sage
Fern Schaefer
Donald Schmidt
Marcella Schnarr
Ray Seed

Suzanne Selby
Nick Sienna
Bruce Simpson
Rosa Zelinda Sirianni
Kenneth Somers
William Sorokolit
Tom Sosnoski
William Spearin
Robert Stanley
Ivan Suggitt
Ted Takahashi
JoAnn Telford
Giuseppe Temprile
Dorothy Thomas
Maryanne Timmermans
Francis Tremblay
Robert Trowbridge
Marinus Van De Ven
Peter Van Vlaanderen
John Vanderkooy
Alexander Vasiliadis
Ferne Virley
Robert Walker
Jacob Wall
Madeline Weppler
Margaret Werden
Donald White
Ewald Wiedmann
Frederick Young
Ronald Young
Roy 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.

CHECK OUT OUR MONTHLY PARKINSON'S WEBINARS!

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