

THE PARKINSON'S update



**“ This disease is
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going through”**

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A MAGAZINE FOR
THE PARKINSON'S
COMMUNITY OF
SOUTHWESTERN
ONTARIO

parkinson SOCIETY
SOUTHWESTERN
ONTARIO

WINTER/SPRING 2023 **ISSUE 77**

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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Front Cover Photo:

Monica Bos knows the importance of being in community. From support groups to exercise, Monica has got involved and connected in the Parkinson's community. Read more of her story on page 6.

FROM THE CEO's DESK



Shelley Rivard

Welcome to 2023! It is always great to usher in a new year filled with excitement and anticipation about what it has in store for us.

2022 was a remarkable year for our organization. As we slowly evolved out of the COVID pandemic and back to in-person programming and events, many were excited to be back, seeing others face to face for the first time in quite a while, and others were a bit reluctant, enjoying the virtual programs. We saw amazing community support of our events, Walk for Parkinson's and the Parkinson Golf Classic. Thank you to everyone for all your support. As well, we have continued to provide both our Spring and Fall Regional Conferences in-person and virtually (a lesson we learned through COVID) which provides access to these educational events no matter where you live within the PSSO region.

In 2022, we were able to expand our staff resources. In May, we welcomed Kassie Harker, our Education Coordinator to the team. In June, thanks to an OTF Grant, we welcomed Meagan Warwick, our Community Engagement & Volunteer Coordinator; and in September, Jessica Halls returned from parental leave and re-joined the team as Manager, Marketing and Communications. Parkinson Society Southwestern Ontario has an amazing staff team dedicated to meeting the needs of our clients, volunteers and donors throughout the Parkinson Community.

Planning has begun on all 2023 programs and services, conferences, webinars and workshops, fundraising events and our Graduate Student Scholarship Program. New in 2022 was our Dance for Parkinson's which was been a huge success. We are excited to look to expand this program in 2023. This year, our Spring Regional Parkinson's Conference will be held in Windsor, with the Fall Regional Parkinson's Conference in October. Our Parkinson Golf Classic in partnership with Velikonja Financial of CIBC Private Wealth is taking place May 31, 2023 and our Walk for Parkinson's will be on September 9 & 10. Keep up to date at what is happening at PSSO through the website, pssso.ca.

This year, we would like to reconnect by getting back into the community. Our hope is to connect with as many of you as possible through visiting support groups, meeting you at our education events, or walking with you at our annual Walk for Parkinson's.

As well, we are focused on building diversified and sustainable sources of revenue. One of those sources of revenue is through funding requests from foundations, government and corporations. When requesting such funding, a strong supportive membership demonstrates a commitment to the work of our organization. It builds credibility and connection to our community and lends weight to our requests. If you would like to join our Hero of Hope Membership program, please connect with me for further information.

As we move forward in 2023, I hope that you will reconnect and get involved in all that PSSO has to offer in your community. You are never far from HOME with Parkinson Society Southwestern Ontario.

Shelley Rivard

Shelley Rivard,
CEO



APRIL AWARENESS in 2023

This April, we plan to show the true impact of Parkinson's disease in the lives of clients, carepartners, family members, etc.

We often hear from you that you wish people really understood what Parkinson's is ... beyond the tremor.

So, this April, we hope you will join us in spreading this message. There will be online visuals, community posters, radio conversations and more.

Be part of the conversation.

Show the reality by being willing to talk to people in your life about what you experience on a day to day basis.

Take action and respond by participating in what we put out during the month of April. Write to local dignitaries, share our social media posts, our collective voice is what will make us heard.

Finally, on World Parkinson's Day, we will hold a celebration at our office to commemorate and recognize the amazing people we have in our community. We may

be facing hard realities but it doesn't stop us from being strong, capable and a fighter.

We look forward to showing the Southwestern Ontario community what Parkinson's is all about.

Stay tuned for more ways to get connected on this project. In the meantime, if you're interested in being part of our April Awareness initiatives, contact Jessica Halls, Manager of Marketing and Communications to learn more.

Share your voice

by submitting your story. Contact
Jessica Halls, Manager of Marketing &
Communications at Jessica.halls@psso.ca

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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.



THANK YOU for raising over \$410,000!



Celebrating the Success of Walk for Parkinson's

On September 10 and 11, our exciting in-person walks returned across Southwestern Ontario and featured entertainment, food, prizes and more! Across the region, 1360 participants and 80 teams came together to support their loved ones and friends living with Parkinson's disease. Everyone brought their enthusiasm and energy to make this event memorable for all involved. To view additional photos from each walk, you can check out the galleries section of our website and PSSO's Facebook page.

Money was not the only thing raised. In communities throughout Southwestern Ontario, PSSO clients, families and carepartners raised awareness for Parkinson's – by standing up and letting their friends and neighbours know that while they may have Parkinson's, it doesn't have them.

Mark your calendars for the 2023 **Walk for Parkinson's**, taking place on September 9 and 10, 2023. We look forward to engaging with volunteers in the coming months to begin the planning process. 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.

Remember... every dollar raised through **Walk for Parkinson's** goes towards programs and services that benefit Parkinson's clients throughout Southwestern Ontario. See you September 9 and 10!

TOP WALKERS

Clare Poechman.....	\$15,295
Scott Dunbar.....	\$9,599
Grant Bournier	\$7,708
Bill Schafer.....	\$6,868
Robert Ecclestone	\$6,361
Christine Scheer.....	\$6,339
Wendy Spiegelberg	\$5,700
Carolyn Young	\$5,354
James "Ian" Shouldice	\$5,304
Mary Vernon	\$5,194

2022

WALK for Parkinson's Sponsors



**Toyota Motor
Manufacturing
Canada Inc.**



Bluewater Power Distribution Corp, Boshart Industries Inc., Carson Cleaners, Compass Minerals, CommonWealth Financial Inc., Gates Canada Inc., Hamstra Carpet One, HT&C Mutual Insurance Company, Hunter Steel Sales Ltd., Matchett Financial Services, MicroAge Basics, Qwest Homes, Strathroy Mini Storage, Town of Goderich, Unifor Local 2458, Unifor Local 88, Windsor Factory Supply Ltd.



Bridging Community with Parkinson's Disease

"Going through life without community to support you is hard enough. Going through this disease makes it that much harder," shares Monica Bos. Monica's young onset Parkinson's diagnosis has impacted her life ... but instead of becoming isolated with fear, anxiety and unknowns, Monica has stepped forward in courage to look for community to strengthen her.



"Community is important to keep your spirits up. It is good to surround yourself with people who have the same affliction as you do and can stay positive. The secret to keeping your spirits up is to surround yourself with positive people. Negativity breeds negativity," Monica explains.

Coming out of the last few years, it is hard to try to reorient ourselves in a world that has been changed and shaped by years of uncertainty and fear. It is easy to stay "comfortable" in our own homes and think that it is simpler to do life on our own. But over time, the isolation will have an impact on us as we have seen. We crave community. We crave support. We crave people to help us feel less alone.

"I think it's important to have others in your life who know what you're going through. Family and close friends are of course important, but they don't fully understand what a person with PD goes through every day," says Monica.

Monica has taken it upon herself to invest in community. Monica attends "Coffee Klatch" on Monday mornings. "I love all the people who are there week after week. There's a real sense of family there." Monica also attends "Parkinson's Music Choir" every Friday morning. "Sophia, our instructor, is a ray of sunshine and it's a good opportunity to exercise your voice and see familiar faces". Monica also exercises three days a week, attends the monthly Parkinson's Support Group meetings and the Young Onset Support Group. "All these opportunities to connect allow space to share problems and strategies and connect with others going through the same things you are."

Monica shares that if she were not connected as she is, she would become depressed. "I'm not saying everyone is positive all the time, but even when you're down, you can always find some positivity in a support group to take you to a better place mentally."

This year, we encourage you to get connected. Take a look at psso.ca to learn about all the programs and services available and take even just one small step to getting connected with others.

"This disease is very hard to go through on your own. It's important to surround yourself with people who know what you're going through. And the new friends you make are a bonus!"

To learn more about getting connected in your community, visit www.pssso.ca or contact **Mandy McDonagh** at info@psso.ca

Have you ever watched the stars
fade
grasping at the last moments of
luminescence
as the sun rises to
steal away their shine

have you ever kissed
the trembling hands of
someone you loved
wishing against
all odds that
maybe tomorrow it will be
easier
that their bones no longer
feel tired
and
they can feel like themselves
again

it comes like a thief
quiet and unnoticed,
at first but
painful and lasting in the end

I don't see you different now but
I know you'll never feel the same
as if the earth
dulled the hues of your joy
overcasting your passions with
the feeling that
nothing will feel the same
again

just like the stars, though
you never truly
stop shining

– **Sabrina Bos**,
Monica's daughter

I Have Parkinson's but It Doesn't Have Me: Darryl Walker

My name is Darryl Walker and I was diagnosed with Parkinson's disease five years ago when I was 43 years old. Since my diagnosis, the disease has slowly progressed. Cramps in my feet seem to be the latest gift that Parkinson's has given me. For the most part, my medications have done a good job keeping my symptoms manageable, but getting the dosages just right seems to always be a work in progress. My main challenges are fatigue, tremor and the loss of some of the fine motor function in my left hand. I work as an engineer and my job entails quite a bit of reading and writing reports. Unfortunately, typing has become a bit of a challenge, but I have a great employer willing to help me modify the way I do my work. For the most part, this allows me to perform my duties as if I did not even have Parkinson's disease.



In addition to my career as an engineer, our family has a honeybee farm. Some of my favourite time in the summer is spent in our bee yards. One part of our honeybee operation is raising queen bees for our own farm and for sale. Without getting too far into the details, raising queen bees starts with moving a very tiny larva (which is smaller than half a grain of rice) with a special tool into a tiny cup without touching the walls of the cup. It's kind of like a weird game of Operation. It takes a very fine touch. I am sure you can imagine how difficult this has gotten as my Parkinson's disease has progressed; I have had to give up this part of the work. Looking back, beekeeping has honestly been a blessing. I am fortunate to have a great family and the privilege of training our next generation of family beekeepers to continue this work.

I did have to give up curling a few years ago. Somehow it seemed unwise for a person with Parkinson's, not being super stable on my feet, to slide around on a sheet of ice. The last thing I need with my Parkinson's is a head injury. About three years ago I rediscovered sailing, I used to sail when I was a teenager. I have found that sailing is one activity that fully focuses my attention. Sometimes I even forget that I have Parkinson's. Usually this happens at times when we are nearly colliding with another sailboat, or if there is a big gust of wind almost capsizing the boat.

The one thing that I would like to share with someone who has been newly diagnosed with Parkinson's disease is to keep an eye on your mental health. Depression and anxiety are common symptoms for people with Parkinson's disease. I know that when I physically do not feel well, my mental health suffers. This has been a struggle for me throughout my walk with this disease. If you are struggling with your mental health, you are not alone and there is lots of help available.

When I first got my diagnosis, it was probably one of the most difficult times in my life. For the most part, this disease has progressed slowly. Reflecting on the past five years, I know that I will need to continually adjust my life as the disease progresses. But I also know that I am still the same person I was five years ago and I will continue to be that same person. I may walk a bit slower, I may get tired more easily and I may not be able to do the same stuff that I always could do, but I am still the same person that I was before I was diagnosed with Parkinson's disease. I have Parkinson's, but it doesn't have me.

ASK THE EXPERT

Dr. Didyk has been a geriatrician/internist in Waterloo Region since 2004. Prior to that, she worked in Calgary and Hamilton, after completing medical training and residency at McMaster University. Nicole is an associate clinical professor at McMaster and has been involved in medical education at the Waterloo Regional Campus. Dr. Didyk's passion for education has led to the launch of The Wrinkle, an online educational resource for older adults, their carepartners and health professionals. Catch up with her at www.TheWrinkle.ca!



1. Constipation is a common and challenging symptom with Parkinson's disease. What are the best methods to improve bowel movements?

Parkinson's can slow down colonic transit and cause constipation. For starters, I recommend reviewing all medications to make sure there are not any on your list that can worsen constipation (like water pills, some bladder medications, narcotic pain relievers and iron supplements).

Next, diet and fluid intake changes can make a big difference! Prunes are great, with ½ cup, or 50g of prunes containing 6 grams of soluble fibre. Other fibre sources include beans, oats, wheat bran and sweet potatoes. Aim for 2 litres of water or other fluids per day, unless you have been told to restrict fluids for some other medical issue.

The laxative that I prescribe most often is Polyethylene glycol (aka PEG 3350 or Restoralax). This is an osmotic agent that draws water into the colon and is safe for daily use for up to 24 months, if needed. Stimulants, like senna, can stimulate the colon to move more quickly. Some people need a combination of things to get their bowel movements sorted out, and it can take some trial and error.

2. Winter is cold and flu season. Are those living with Parkinson's at higher risk of complications when contracting the Influenza flu virus? How beneficial is the annual flu shot at preventing complications?

Those aged 65 plus are at higher risk of getting complications from the flu, but Parkinson's disease by itself does not seem to increase flu complication risk. Nonetheless, getting a high-dose flu shot is what I recommend for every older adult.

The effectiveness of a flu shot at preventing illness from the flu ranges between 40 – 60% (it varies from year to year). It can reduce the risk of hospitalization in older adults by 40%, and the risk of being admitted to an ICU by 82%.

If you are 65 or over, also check to see if your pneumococcal vaccine is up to date. Being vaccinated for flu and pneumococcus reduces the risk of pneumonia (which can be a flu complication) and death. Time to roll up your sleeve!

3. I experience on-going anxiety and hear more about the importance of taking care of your mental health. How does someone start to take care of their mental health? What options are effective?

First, know that you are not alone – up to 50% of those living with Parkinson's have anxiety symptoms. Reaching out to your network of friends and peers (or to PSSO) can be a good way to start. They may be able to share what worked for them if they had a similar challenge.

Non-medication strategies can include exercise, mindfulness-based meditation and cognitive behavioural therapy (CBT). Some therapy can be done online (check out www.anxietycanada.com).

Medications can help, such as antidepressants that have anti-anxiety activity. Serotonin reuptake inhibitors, or SSRI's, are commonly prescribed for anxiety. I avoid benzodiazepines (like valium) if possible, as they increase fall risk in older adults and can cause drowsiness. An adjustment in Parkinson's meds can help in certain situations. Carepartners are at risk of anxiety too and should consider reaching out for help if they need it.

4. What are biomarkers? Why are they related to my overall health? And how do I check biomarkers?

A biomarker is any measurable characteristic that indicates a biological state or condition. Examples include a blood test, biopsy, scan or reading (like a blood pressure measurement). Often, a biomarker is used to detect a disease at an early stage before other signs or symptoms emerge. This is especially helpful if there is a treatment or lifestyle change that could delay disease onset.

Currently, there isn't a good, reliable, easily accessible biomarker for Parkinson's disease. There have been studies looking at whether a protein called alpha-synuclein can be detected in skin biopsies, or cerebrospinal fluid (from a spinal tap). The test cannot distinguish between Parkinson's and other "synucleinopathies" (like Lewy body disease). We do not have an effective treatment, so we don't use this test in practice.

The most important biomarkers are those that your doctor regularly does in the office, like checking blood pressure, weight circumference, bone mineral density and so on. More blood tests don't usually lead to better health!

ASK THE EXPERT

1. Fatigue is a common symptom for those living with Parkinson's disease. How can one best manage their fatigue and daytime sleepiness?

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.



Fatigue and daytime sleepiness are two different symptoms. Fatigue is related to a feeling of lack of energy, reducing the ability to manage activities of daily living, exercise or tasks required for work, etc. Fatigue can occur at any time during the day and can last throughout. Fatigue can be a symptom of Parkinson's disease that is independent of motor symptoms. This means that patients can have tremendous feelings of fatigue at the onset of the disease before other symptoms such as tremors, stiffness and slowness are visible. Due to such difficulty with fatigue, patients are unable to function and a diagnosis of Parkinson's disease is not made as the classical symptoms and signs are missing. The doctor assumes the fatigue is another medical problem and does not treat it as a symptom of Parkinson's disease.

Fatigue can also occur during the course of the illness. Patients then do not always present with fatigue at the beginning but rather during their illness. This is similar to the fatigue at the beginning of the disease and the important point is both these types of fatigue can be responsive to typical Parkinson's disease medications such as Levodopa. Therefore, as motor symptoms such as stiffness, slowness and gait difficulty are responsive to dopaminergic therapy, so can fatigue. When fatigue happens during the illness, patients can have a "wearing off" of Levodopa if they are on dopaminergic therapy, then fatigue can also respond to Levodopa in terms of alleviation of fatigue during "wearing off" if dopaminergic therapy is adjusted.

It is important to remember that fatigue can result from anemia, hypothyroidism or other systemic diseases which need to be investigated. Simply having fatigue when someone has Parkinson's disease does not mean it is related to Parkinson's disease. Therefore, an investigation should be done by the family doctor. Vitamin deficiencies such as B12 may cause fatigue or iron deficiency. Finally, fatigue can result from dopaminergic medications, or side effects of drugs such as anti-hypertensives used for blood pressure treatment. If the blood pressure is too low, then fatigue can occur.

Daytime sleepiness is different. Patients may not feel tired due to fatigue but rather poor sleep hygiene. Patients with Parkinson's disease can have poor sleep hygiene, meaning they cannot sleep through the night, which is a symptom called frequent awakenings. Patients wake up in their sleep cycle due to the neurodegenerative issues of Parkinson's disease. If this happens, the physician needs to use medications to try to improve the sleep cycle. Once the sleep cycle is adjusted, it is likely that daytime drowsiness will reduce dramatically.

There are also issues with rigidity, stiffness and difficulty mobilizing occurring at night which can interrupt sleep. Treatment of primary Parkinson's disease symptoms to alleviate those symptoms can improve sleep quality, helping the daytime sleepiness. Medications for Parkinson's disease can cause awakening. This needs to be adjusted by the treating Parkinson's disease doctor to reduce nocturnal lack of sleep. Other symptoms such as gastric reflux, hallucinations, urinary tract infections all have an impact on nighttime sleep causing daytime sleepiness.

Daytime sleepiness can occur due to medications. Dopaminergic medications can cause sleepiness and needs to be addressed with the treating doctor by how much medication and when they take it, etc. If the patient is not engaged with activities, the default is to feel sleepy and take long naps, causing a problem with the 24-hour sleep schedule, and ending up with a bad sleep hygiene cycle. Since there are many factors for fatigue and daytime sleepiness, it is not possible to advise one medication to take. We do sometimes use stimulants such as Methylphenidate from time to time to help patients with daytime sleepiness, but this should be discussed in detail with your doctor.

Finally, special disorders such as restless leg syndrome, often treated with dopamine agonist drugs such as pramipexole low dose at night, sleep apnea (need sleep study) and even REM behavior disorder can impact sleep quality.

I cannot tolerate pain medications such as anti-inflammatories or opioids and experience Parkinson's disease-related pain for years. What are some evidence-based ways to manage pain?

Pain is a very non-specific problem. Pain can be a symptom of Parkinson's disease itself. The best way to manage is to adjust and modify the dopaminergic medications for pain. Dopamine is the best way to manage pain. Anti-inflammatories or opioids cannot be used long-term. There is no evidence-based way to manage pain for Parkinson's disease. As mentioned, dopaminergic therapy remains the mainstay. For nocturnal pain, using drugs throughout the night can be used. If dopaminergic therapy is working but patients require high doses of medications, DBS (deep brain stimulation) or pump therapies with Duodopa can be helpful.

Pain in PD can be present at the beginning of the condition and is usually localized to the neck and shoulder. Then there is diffuse non-localizing pain which means it is everywhere and makes you feel very uncomfortable. Finally, there is pain that is a result of wearing off of the levodopa often in the morning and in the feet/legs.

Focal symptoms such as toe-curling or the big toe being up and twisted can cause leg pain, and cramps. Targeted therapy such as Botox injections can be helpful for pain. Pain management in general is a specialized therapy and assessment in a Pain Clinic can be useful. Long-term use of anti-inflammatories, opioids or even cannabis is not recommended in general for patients with Parkinson's disease.

Parkinson's disease can present with a range of symptoms and many medications have various side effects. How can one separate what is a symptom of Parkinson's disease or a side effect of medications?

If the symptoms began before taking medications or occur after taking medications, then it is a sign of medications. If this is not the case, discussion with your doctor becomes important. Your physician should know what signs and symptoms are Parkinson's disease-related and what are related to drug use. For example, if you take medication during the day and hallucinate only at night, it is unlikely medication related as it is possible that the medication is being consumed during the day. It is possible that the medication is acting at night introducing side effects, but hallucinations may be a primary symptom. If you feel lightheaded with a high dose of Levodopa during the day, it may not be medication related but simply that you are not drinking enough during the day. These things need to be worked out by your healthcare team, specifically your Parkinson's disease doctor or nurse.

I have heard about MRI-guided focused ultrasound for the treatment of Parkinson's disease which is less invasive than DBS. What can you tell me about this treatment?

MRI-guided focused ultrasound is a lesional surgery. From a historical perspective, lesion surgery was being done even 100 years ago for Parkinson's disease management. The ability to target and do procedures with imaging was not done then but it was well-known that making lesions in the deep structures of the basal ganglia could reduce Parkinson's disease symptoms. When it was resurrected radio frequency guided ablation was being used to make lesions, opening the skull with a small hole and using probes to localize which deep target was to be lesioned. The probe was heated to make the lesion deep in the brain and the invasiveness was that the procedure had to be done with a small craniotomy hole that had to heal and had risk of infection, etc. The risk was small because the surgical techniques were highly specialized. The ability to do imaging with a much higher precision of looking at these small targets with MRI was used in pairing with the recordings.

Deep brain stimulation continued this approach. except that instead of heat making, the heat base lesion probes were left in there and connected with a pacemaker to allow electrical current to be passed in the same deep structures that are also programmable making the contacts available in the deep brain can be selected in multiple regions to provide precise current inside the brain and can be turned off to alleviate any side effects. This is not the same with lesional surgery, where once the lesion is made it's irreversible. It can't be "programmed" in that you can't do the procedure multiple times to change and sculpt the lesions with repeated procedures.

MRI guided focused ultrasound has taken the focused ultrasound approach rather than the radio frequency ablation approach where a whole bunch of ultrasonic transmitters are used to focus a beam into the deep structures and a lesion is still made.

The procedure is not non-invasive in that there is still a lesion placed in the brain. The non-invasive part is not having to do that small hole where a probe needs to be placed in the brain. Other than that it is still lesional surgery. The lesional part is still what has been done in the past. This is a one-time procedure, a lesion is made which is not programmable or reversible. The decision on which kind of procedure to be done is decided by the patient and the criteria they may meet which is decided by the treating Parkinson's disease doctor and surgeons who do the procedures.

My loved one has Parkinson's disease and is beginning to experience visual hallucinations. What are visual hallucinations and what are the best strategies for carepartners to help loved ones with hallucinations?

Visual hallucinations are those symptoms where a patient feels a presence in their vision or actually sees things such as insects, or even children.

Patients that hallucinate at the beginning of Parkinson's disease may not have Parkinson's disease at all. This is a sign and warning of diffuse degeneration than what we see in typical Parkinson's disease. For example, a condition such as diffuse Lewy body disease can present with early hallucinations, cognitive impairment and Parkinsonism and this is not typical Parkinson's disease.

Patients that have been diagnosed with Parkinson's disease can have hallucinations as side effects from medications. Dopamine agonists such as Pramipexole or Amantadine can cause hallucinations and if they have started when medications are initiated, then this would be a side effect and the doctor can adjust medications to get rid of the hallucinations. Sometimes we can't change or reduce medications because it has produced good symptoms benefit, that if we change, other functions may deteriorate. If hallucinations are mild, we may not treat them. If symptoms are mild to moderate and have some issue with no awareness by patient or caregiver, but we can't reduce medications then we would use other medications to treat this so that we can keep the other medications the same.

It is possible that visual hallucinations are caused by something like pneumonia or urinary tract infection, causing Parkinson's disease medications to react differently resulting in visual hallucinations. If this is the case, the primary symptoms need to be treated. For example, it is common for us if a patient has sudden hallucinations, then we will have the family doctor perform a urinalysis or blood test to make sure there isn't a systemic illness.

In advanced Parkinson's disease visual hallucinations can be part of the cognitive impairment. If visual hallucinations decline early, then the diagnosis is different than Parkinson's disease. In advanced Parkinson's disease, if there is cognitive decline along with motor symptoms, 10-15 years into the disease, this is a syndrome of involvement of areas of the brain outside the typical Parkinson's disease domain, but now we include this as part of the Parkinson's disease and dementia state. The treatment of visual hallucinations needs to be discussed with your family doctor or Parkinson's disease doctor for best management.

WORLD PARKINSON'S DAY CELEBRATION

Join us as we review the impact over the last year. Hear stories on the success and achievements and celebrate the amazing community we have in a World Parkinson's Day celebration with us.

The event will feature research presentations and refreshments will be provided.

Tuesday, April 11th at 5:00pm
Parkinson Society Southwestern Ontario
123-4096 Meadowbrook Drive
London, ON



What's Mine to Control

Sometimes I get myself in a tizzy trying to change other people's behaviour. This is the emotional equivalent of attempting to shove a boulder up an icy hill while wearing roller skates. It is exhausting and impossible. I get irritated and resentful and it is even more fun for the person whose behaviour I am trying to change.

I understand, and even appreciate, why I do it. The more stressed I get, the more controlling I get. This seems to be my default stress mechanism, and I think it kicks in to try to protect me and the people I love. However, I keep learning and re-learning, that you cannot change other people or their behaviour. Thinking you know what's best for them does not mean knowing what is best for them. No matter how life-changing you think your idea is if the person does not want to do it, it is not going to happen.

Let's be realistic. As a lifelong fixer, I am not going to suddenly become this person who lives and lets live without ever stepping in the puddle of pushiness. Sometimes, now, I notice what I'm up to and noticing allows me to choose.

When I am spending a lot of energy on things I cannot control, it does not leave much (or any) energy left for the things I can do something about. As a carepartner, I can choose what and when I read about Parkinson's. I can make choices about the things I do to care for myself. When something, anything, happens, I can choose to pause before I respond. Depending on the circumstance, the pause might last an hour, a week or a month, and sometimes the pause might only be the length of a breath or two.

Every life has seasons of overwhelm. If you are in one of those seasons right now, consider this reflection exercise to help you conserve and redirect your energy. Choose one area of difficulty you are currently facing that you would like to reflect on for a moment. Draw a circle and inside the circle, write three things currently within your control in relation to this difficulty. Outside your circle, write three things that are outside of your control in this situation.

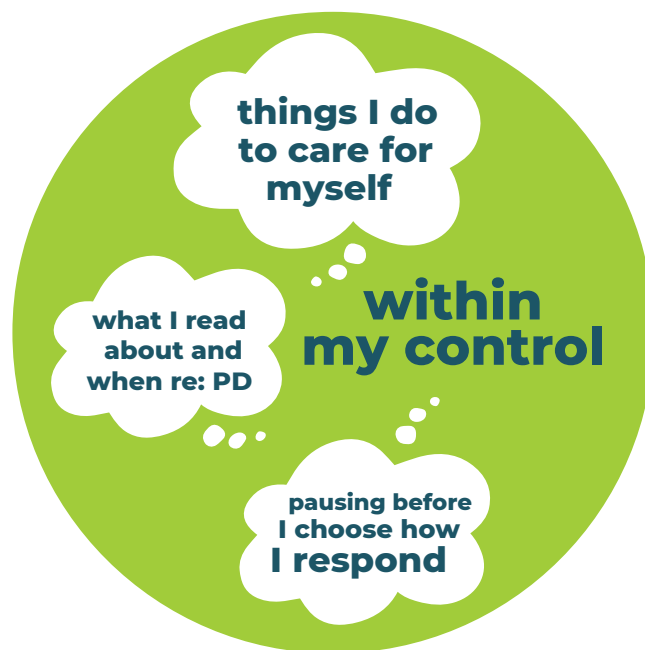
Noting what's beyond your control here might feel painful, or it might feel like a relief, or it might be both and more. That is okay, all feelings are welcome here. They will move along when they are ready and when you are ready, you can use some of your precious and limited energy to work with what's inside your circle.



Rebecca Higgins is a writer, mental health educator and carepartner. Find her at www.mentalhealthworkshoptoronto.com.



outside my control



Carepartner Resource Support Toolkit

A carepartners function is an essential role, serving individuals in need of care in many forms. Although being a carepartner reflects strength and positivity, individuals in carepartner roles need access to resources which help support their mental health, financial stability and personal wellbeing. According to the Research Institute of Aging (n.d.), providing care is rewarding and allows for opportunities for personal growth. However, the reality of caregiving involving challenges and overwhelming experiences must be acknowledged. "Regardless of the roles you take on as a carepartner, the most important thing to remember is not to lose yourself in this journey. You need to ensure that you are utilizing resources that will best help you as a carepartner" (Role, Health, and Well-being, n.d.).

The reality is that the sustainability of effective caretaking requires one to also take care of oneself. Most carepartners are untrained. Data has shown carepartners face challenges which force them to learn as they go to support a person with Parkinson's (Dizon, 2022). The Davis Phinney Foundation (2022) provides a detailed digital toolbox with resource links about communication, general caregiving, legal, medication, safety, transportation and self-care tools. Multiple learning curve areas come up with caretaking, and having a toolkit of resources is beneficial to minimizing the time it takes to solve problems. Exploration of resources also leads to the discovery of entitled supports such as tax benefits, financial resources and carepartner leave opportunities.

A great outlet of support for carepartner is Home and Community Care Support Services, a resource which helps reduce carepartner burden. Assistance from healthcare professionals allows for the development of individualized care plans, working closely with the primary carepartner (Richie, 2022). Getting started involves navigating the website healthcareathome.ca to access the community care support available in your community. If an individual holds a valid OHIP card, they are eligible to receive an assessment which will allow for access to various services, depending on the needs of the client.

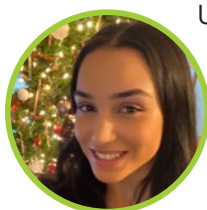
As a carepartner, utilizing tax credit programs is a great way to help with financial expenses. Financial services companies offer the opportunity to speak to representatives about tax credit eligibility. These companies' websites detail non-refundable tax credits available for carepartners, such as medical expense tax credit, disability tax credit, home accessibility tax credit and Canada carepartner credit. Such benefits can be applied for by using the individualized links for redirection to the specific tax credit claims on the Canada Revenue Agency website. Aside from navigating applications on the CRA website, agents can also be reached over the phone. If one is a carepartner residing in Ontario and unsure what tax credits are available, it is best to call the CRA number 1-800-959-8281 to speak to a representative for help with the application processes.

Caregiving often translates to medical expenses. An additional expense reimbursement opportunity is the Ontario Seniors Care at Home tax credit. This refundable personal income tax credit program allows seniors with eligible medical expenses to receive funding for coverage of essential costs (Ontario.ca, n.d.). This benefit can be reviewed at <https://www.ontario.ca/page/ontario-seniors-care-home-tax-credit>. By contacting the CRA, eligibility for making expense claims on your tax benefit return can be confirmed. Importantly, keeping medical expense receipts, for big or small purchases, is always the best idea to ensure expenses can be reimbursed within any government tax credit program.

List of **Resources:**

- davisphinneyfoundation.org
- Home and Community Care Support Services <https://healthcareathome.ca/home>
- <https://www.sunlife.ca/en/tools-and-resources/money-and-finance/managing-your-money/4-important-tax-credits-that-help-caregivers/>
- Canada Revenue Agency 1-800-959-8281 & <https://www.canada.ca/en/revenue-agency.html>
- <https://www.ontario.ca/page/ontario-seniors-care-home-tax-credit>

Undoubtedly carepartners should take full advantage of resources which, despite differences among each program and organization, allow for extra help.



Hello, my name is Mia! I am in my fourth year of study in the Social Work and Disability Studies program at the University of Windsor. I love this career field as I am able to support and advocate for people. In my spare time, I love to volunteer within my community and exercise at the gym. I also consider myself an avid reader.



Dr. Nicole Didyk,
MD FRCP(C)



Sophia Christopher,
MTA, RP, NMT-F



Dr. Olga L. Rojas,
MD, PhD



Dr. Quincy Almeida PhD

2022 FALL CONFERENCE HIGHLIGHTS

Fall Regional Parkinson's Conference took place this year in Kitchener on October 22, 2022 at the DoubleTree by Hilton. It was a wonderful day to build connections and show how all our strengths can better support each other.

Our four event speakers, Dr. Didyk, Sophia Christopher, Dr. Rojas and Dr. Almeida shared their knowledge and expertise through a range of Parkinson's education, treatment options and growing research. Movement break facilitators Crystal Hughes and Pauline Shore had us moving and learning about all the important ways "movement is medicine".

Thank you to our corporate sponsors AbbVie, Sunovion Pharmaceuticals Inc., Paladin Labs Inc., along with our community sponsors Lanark Village Retirement Residence, Right at Home Canada Waterloo-Wellington, Sara Lodge Nutrition, The Village of Winston Park and Silver Cross Kitchener. Without your support, events like this are not possible.

PSSO thanks everyone who joined us for their participation and support, both in-person and virtually. We are part of a bigger community, a family of people all connected through support right here at home.



Volunteers Needed - Support Group Facilitators

Looking for Support Group Facilitators in various locations across Southwestern Ontario

This position will work in conjunction with PSSO staff to provide education and support at monthly support group meetings to clients living with Parkinson's, their carepartners and family members. The Support Group Facilitator will provide leadership and create a safe and empathetic space for clients to share experiences, ideas and feelings. This role will also help address challenges, encourage the development of supportive relationships and provide an overall inclusive atmosphere where people can be themselves.

For more information, contact Meagan at meagan.warwick@pssso.ca or 1.888.851.7376 ext. 207



The MIND Diet

Research suggests that Mediterranean and DASH diets are involved in maintaining brain function. These diets improve heart health and reduce stroke risk, which can help protect the brain. Understanding the important benefits of these dietary interventions, Dr. Martha Clare Morris and colleagues set out to identify precisely which foods from these two diets can preserve cognitive function. As such, the MIND diet was born.

The researchers divided foods from the DASH and Mediterranean diets into "brain healthy" and "unhealthy" categories. Foods included in the "brain healthy" category include green leafy vegetables, other vegetables, nuts, berries, beans, whole grains, seafood, poultry, and olive oil. Foods included in the "unhealthy" group include red meats, butter and stick margarine, cheese, pastries, sweets, and fried or fast foods. They developed the MIND Diet Score, where a higher score is linked to consuming brain healthy foods more often and unhealthy foods less often. The study found that patients with higher MIND Diet scores had a slower rate of decline in their brain function as they got older. This evidence demonstrates that following the MIND diet may help protect the brain as we age.

The emergence of further research suggests that the MIND Diet may also help reduce the risk of Alzheimer's Disease and improve heart health and diabetes. As the MIND Diet's positive association with brain function has been established, there has been more interest in determining its impact on Parkinson's disease.

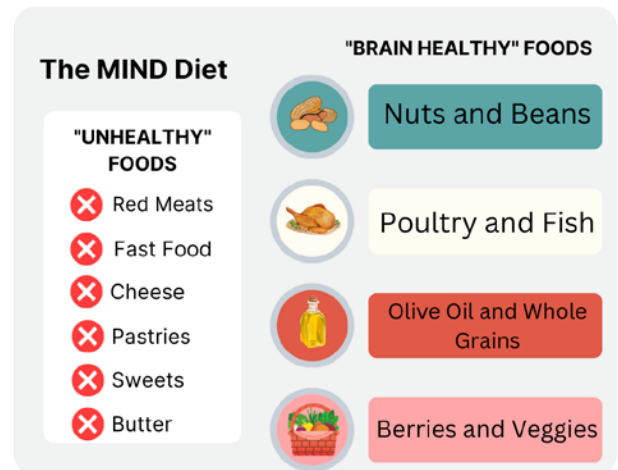
A 2021 study by Dr. Avril Metcalfe-Roach and colleagues found that following the MIND Diet was associated with an older age of onset of Parkinson's disease, especially in women. This noticeable effect in women may be explained by the fact that women better followed the MIND Diet than men. These results suggest a potential association between the MIND Diet and the delayed onset of Parkinson's disease.

Other dietary considerations in Parkinson's disease are related to medication administration. One of the most common medications used to treat motor symptoms is Levodopa. Eating protein-rich meals can interfere with the absorption of Levodopa, causing a delayed onset of medication action. Therefore, Levodopa should be taken 30 minutes to 1 hour before or 2 hours after a meal. Levodopa can also cause nausea. As such, taking it with a small, non-protein snack may be helpful if this side effect becomes bothersome.

The foods we choose to nourish our bodies can significantly impact brain health, heart health and other chronic medical conditions. For example, the MIND Diet may slow the rate of brain decline as we age and may play a role in delaying the onset of Parkinson's disease.



Leona Spasik is a pharmacy student at the University of Waterloo that is passionate about geriatric pharmacy. She became interested in Parkinson's disease after her grandfather was diagnosed several years ago. She hopes to empower other Parkinson's disease patients both through her work as a pharmacy student and through volunteering in the community.



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.

The Benefits of Aquatic Therapy for People with Parkinson's Disease

Aquatic therapy is the practice of movement and exercise performed in water and is commonly recommended for those undergoing physical rehabilitation. It is typically done in a pool at above-average temperatures, where qualified therapists guide participants through various exercises. This in-water therapy is now being adopted by those with Parkinson's disease (PD) due to the multiple benefits associated with it. Aquatic therapy can help develop and improve balance, strength and flexibility while reducing fall risk associated with other activities.



Compared to dry-land, aquatic exercise is useful because water helps support a person's weight while they are submerged in it. This allows participants to exercise longer without feeling fatigued. The light resistance of water, which is the pushback you feel when you move through it, is beneficial as well because it allows those with PD to build up strength over time without the use of weights, which could potentially be dangerous. By improving strength, one simultaneously improves stability, balance, flexibility and posture, along with motor and nonmotor symptoms of PD. Water also mitigates the risk and worry of falling while exercising, a serious concern for those with PD, allowing participants to see the benefits of exercise without the concern of injury present when exercising on land.

Research Evidence with Parkinson's Disease

Pain is also a common symptom of PD and can lead to physical decline, disability, as well as an increased tendency to fall. Aquatic tai chi, another form of hydrotherapy, has had positive effects in relieving pain for mild to moderate PD individuals. It involves a series of upper and lower limb movements performed in a slow and rhythmic manner while individuals are in shoulder-deep water. The benefits were investigated in 2017 when researchers at the University of Almería had 15 Parkinson's patients participate in dry-land physiotherapy while an additional 15 participated in aquatic tai chi. They found that there was a significant difference in pain perception for participants in the aquatic tai chi group. Other benefits included increased gait speed, improved balance and fewer falls.

Moreover, aquatic therapy has been received positively by PD participants in Ireland and Australia. They found it beneficial for their well-being to participate at least once a week under the guidance of a credentialed instructor.

Some did have concerns due to their past experiences with water, but by raising awareness and education about aquatic therapy benefits, we can encourage more engagement and ultimately improve the day-to-day lives of those living with Parkinson's.



Alfred Kwan:

Alfred Kwan is in his second year at Western University enrolled in the Medical Sciences

program along with Ivey AEO status. He is interested in exploring Parkinson's treatments and understanding how to best improve the quality of life for those with Parkinson's.

Emaan Rana:

Emaan Rana is a second-year Medical Sciences student at Western University.

She is interested in learning more about neurological disorders like Parkinson's and the individuals (friends, family and patients) who fight against them.



Share Your Story

We want to hear about your perspective living with or impacted by Parkinson's disease. Telling our stories helps us to advocate for each other!

Email your story to Jessica Halls, Manager, Marketing and Communications at jessica.halls@psso.ca



Tips for Sleeping Well

How to Create Good Sleep Hygiene Habits:

- Set up a bedtime routine to relax and wind down before going to bed. For example, going to bed at a consistent time, limiting screen time to one hour before bed, listening to relaxing music, taking a warm bath, watching television or reading a book.
- Avoid caffeine, alcohol, nicotine and other stimulants for at least an hour before bedtime. It is also a good idea to limit the number of liquids consumed before bed to prevent visiting the bathroom during the nighttime.
- Exercise during the day. Try to avoid any rigorous exercising at night as this will prevent the body from relaxing before bedtime.
- Maintain a healthy diet. It is also important to avoid eating large meals at night.
- Spend time outdoors during the day. Exposure to bright, natural light allows our bodies to distinguish nighttime and the necessity to sleep when it gets dark.
- Try over-the-counter sleep aids.
- Limit naps which can interfere with nighttime sleep. Aim to limit naps to 40 minutes at the most per day.

How to Create a Comfortable and Safe Space to Sleep:

- Sleep on a comfortable mattress and pillow. A mattress topper can provide more cushioning to help you feel more comfortable and offer more support.
- Set the temperature in your room a bit cooler or open a window
- Try to avoid sleeping with pets as they take up space on the bed and can disturb you if they make noise. It is ideal if they have their beds in a separate room.
- Create a dark sleeping environment with minimal light.

Parkinson's and Social Work

Social work is a profession that people can encounter at any point in their lives, for any reason. From child advocacy to end-of-life care, there are social workers ready to help at every turn. At Parkinson Society Southwestern Ontario (PSSO), social work students from King's University College provide free, short-term, therapeutic counselling to individuals living with Parkinson's and their loved ones.

The Bachelor of Social Work program is highly specialized and consists of students hoping to learn all they can as they prepare to join the helping profession. PSSO and King's University College have been connected for four years, and the relationship continues as clients see value in the services provided by social work students.

These services are based upon the Ontario College of Social Workers and Social Service Workers (OCSWSSW) code of ethics. The content within the code of ethics centres around the respect, dignity and inherent worth of the client, as well as the professional competency of the social worker (OCSWSSW, 2008). Students take these values that they learn in class and bring them to PSSO, recognizing the need for social work services within this population.

Working with a helping professional on your mental health can have a significant impact on your physical health, as the mind and the body are strongly connected. Does anxiety make your tremors worse? Talking through your most anxious thoughts with a social worker can provide you with the tools to calm both your mind and your body. Is depression keeping you from regular activities of daily living? A social worker can help you learn to practise self-care and stay on top of your treatment plan.

Deciding to see a social worker may be difficult, but it can be a great step in the right direction for anyone living with Parkinson's. Social work students are trained in building client relationships by making others feel valued and heard, and once an individual meets with a social worker, the two can begin building a professional rapport.

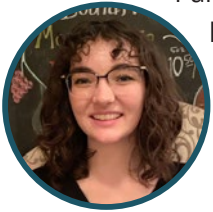


People living with Parkinson's can benefit from the help of a social worker in a myriad of ways. As outlined by the Ontario Association of Social Workers, this can include:

- Having access to individual, family and couples counselling
 - Psychotherapy
 - Stress management
 - Grief, loss and trauma counselling
- and much more (OASW, n.d.).

Amy Chesire, a licensed social worker at Parkinson's Foundation Center of Excellence, says, "A lot of it comes down to the relationship piece—you need to be able to relate to and feel comfortable with a social worker" (Dolhun, 2019).

In many cases, people will enter a relationship with a social worker in a considerably vulnerable state. That vulnerability may feel frightening, but it serves as the foundation for the exploration of one's own thoughts, feelings and experiences. Additionally, it can aid the formation of a strong and healthy professional relationship between the client and the social worker.



Parkinson Society Southwestern Ontario creates a unique opportunity for students to apply what they have learned in their program to real world practice. In turn, people living with Parkinson's can access the services of those students who are inquisitive, compassionate and ready to help.

Paige LaPier is a fourth-year student in the Bachelor of Social Work program at King's University College. Paige has the opportunity to provide short-term personal counselling at PSSO through her program and is looking to pursue a career in personal counselling as well.

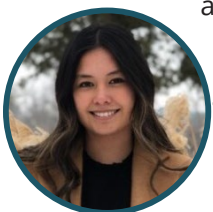
Putting Your Best Foot Forward

An area of our bodies that is often overlooked when it comes to our overall health is our feet. Having healthy and happy feet is an essential part of our health as it allows us to remain active, provides us with stability and more. This becomes even more vital for those diagnosed with Parkinson's disease (PD), as the onset of motor symptoms can have a significant impact on both an individual's mobility and stability.

One of the symptoms which those with PD often experience is a change in walking pattern, known as gait. Instead of the normal heel-to-toe walking pattern, increased stiffness in muscles often leads to a more flat-footed gait. Those with PD will often find that their strides begin to get shorter, and instead of striking the ground with their heel, they push off the ground with their toes (Hausdorff, 2009). This flat-footed walk and overall stiffness in the muscles can lead to various issues in the feet that can be easily managed with proper care. With increased pressure on the soles of the feet, the skin in this area often becomes hard and can be very painful (Parkinson's UK, n.d.). In addition, swelling is common in those with PD, especially those who have difficulties with mobility. As movement decreases, the fluid builds up in the lower extremities resulting in swelling. Finally, Dystonia, a movement disorder causing involuntary contractions in muscles, can develop in those with PD. This may cause an individual's toes to curl or their ankles to turn inwards (making it difficult to walk) and discomfort (Parkinson's UK, n.d.).

The chances of the above issues occurring can be reduced through preventive foot health (IPFH, 2016). The first aspect of preventive foot health is maintaining proper foot hygiene through regularly inspecting your feet for changes, washing daily and wearing clean and dry socks. In addition, maintaining regular physical activity is important as it increases circulation in the extremities and reduces swelling throughout the body. Lastly, it is important to wear well-fitting socks and shoes which provide good stability and are both comfortable and breathable.

To learn more, ask your primary care provider about how the health of your feet can affect you, or consider seeing a Podiatrist, a medical professional that specializes in treating conditions related to the foot and the surrounding area. You can visit the Ontario Podiatric Medical Association (<http://www.opma.ca/>) to find a podiatrist near you and to learn more about how they can serve you. Additionally, physical or occupational therapists can provide exercises and/or treatments to improve your foot health and mobility.



Hannah is currently a fourth-year student at the University of Waterloo studying Biochemistry. She is from Richmond Hill, ON and is an aspiring Genetic Counsellor. She hopes to continue to increase awareness about neurodegenerative disorders and to keep supporting those affected by PD in southwestern Ontario.

Combating Depression in Parkinson's Disease

Do you experience overwhelming feelings of sadness, hopelessness, or loss of interest in activities that you used to enjoy? If so, you may be living with depression, a common mood disorder that affects many people with Parkinson's disease (PD). A recent study by Cong and Colleagues (2022) found that based on over

38,000 participants, 38% of people with PD were living with depression. Other research estimates that this number may be even larger, with up to 50% of people with PD experiencing depression. Needless to say, if you have been diagnosed with depression or think that you may be depressed, you are not alone!

Although depression is common in PD, many do not seek help for it. Individuals may believe that depression is unavoidable with their diagnosis, or symptoms may go unrecognized. If left untreated, depression can worsen PD symptoms by slowing movement, speech and cognition even further. By identifying and treating depression as soon as possible, this can help improve your PD symptoms and quality of life.

Finding Relief from Depression

There is no one-size-fits-all approach for managing depression. Some people find relief through lifestyle changes, therapy, medications or a combination of methods. You should always consult your healthcare provider to discuss which interventions may work best for you and your treatment plan.

Psychotherapy

Psychotherapy involves a variety of talk therapy and counselling. For example, cognitive behavioural therapy (CBT) has shown reduced depressive symptoms by changing negative behaviours and thinking patterns.

Complementary Therapies

Meditation, music therapy, aromatherapy, pet therapy and massage therapy are a few examples of complementary therapies that may assist in reducing symptoms of depression in PD.

“There is hope, even when your brain tells you there isn’t.”

— John Green

Exercise

Research has shown repeatedly that exercise can improve depressive symptoms in PD. Various forms of exercise have shown positive effects, including aerobic exercise, yoga and dance, for example.

Nutrition

There is no one diet recommended for everyone, but generally, your diet should include fruits and vegetables, whole grains, lean proteins such as fish and yogurt, nuts, seeds and beans. Foods with added sugars and fat, such as butter, bread, cereal and processed meats may negatively impact depressive symptoms if consumed regularly. Drinking lots of water and limiting consumption of alcohol may also reduce depressive symptoms.

Medication

Medication, such as selective serotonin reuptake inhibitors (SSRIs), are often used to treat depression. Serotonin is a chemical in our brain which contributes to our mood and happiness. It may take some trial and error to find the right medication that works for you.

Transcranial Magnetic Stimulation (TMS)

A painless procedure that has been shown to reduce depressive symptoms through magnetic pulses in the brain, TMS may be an effective way to reduce depressive symptoms in PD.

Additional Tips for Coping with Depression

- 1) Connect with others in the PD community at PSSO support groups. New members are always welcome!
- 2) Plan small goals that you can achieve every day to boost feelings of accomplishment, such as calling a friend or doing a chore.
- 3) Take part in social activities to avoid feeling isolated, such as volunteering in the community.

See references on page 27.

Electroconvulsive Therapy

Under general anesthesia, small electric currents are transferred through the brain, which proves to be effective in reducing depression in PD. ECT is only recommended when other treatment options do not work.



WHO WILL YOU WALK FOR?

Walk for Parkinson's September 9 & 10

Join the PD community this September 9 or 10 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 all of the fun and engaging activities you have come to enjoy from previous years. Come for the walk, but stay for the fun, entertainment, refreshments and social interactions with friends and community members. We look forward to seeing all of you this September!

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

walkforPD.ca



CLOTHING DRIVE

Looking to clear away some of those clothes that are just taking up space? Don't just drop them at your local thrift store, let us take them off your hands. All proceeds go towards supporting [Parkinson Society Southwestern Ontario](#).

At this time, we are accepting gently used clothing, shoes, and other apparel.

Donating is easy! Just text [519.859.2029](tel:519.859.2029) or email giving.sustainably@gmail.com with your home address and we will coordinate with you a convenient pick up time.

Giving Sustainably was created to inspire others that the generosity of giving is a constant reminder that our actions have life changing impacts on people. This allows us to provide for those in need and help grow our community in a meaningful way.



GIVING SUSTAINABLY
www.givingsustainably.org

parkinson SOCIETY
SOUTHWESTERN
ONTARIO



Gabi Enk, Irene Brooks, Ria Feddes, Lise Ellacott & Paula Deering

Huron County Community in Action

Carol McDonnell, Paula Deering and Lise Ellacott are three wonderful individuals who are part of the volunteer team at Parkinson Society Southwestern Ontario (PSSO). These three women reside in and serve the Huron County community and bring years of experience to their volunteer positions.

"We are all living with Parkinson's when someone we love has been diagnosed."

— Carol McDonnell

Carol McDonnell is a longstanding PSSO volunteer who is the founder of the Parkinson's Support Group in Goderich and was dedicated to the role of Support Group Facilitator for seven years. Carol comes from a background of successors, Paula Deering and Lise Ellacott, to teaching and really incorporated this experience into her facilitation style within the support group. Her husband was diagnosed with Parkinson's and she saw the great need in her community to bring additional support to those impacted by PD. Carol also provided integral leadership to the Walk for Parkinson's in the Goderich community for many years. Her ongoing commitment and leadership throughout her involvement with PSSO are truly admirable. Carol really captured the experience of many of our carepartners and community members when she said "We are all living with Parkinson's when someone we love has been diagnosed."

Carol more recently passed the torch to her successors Paula Deering and Lise Ellacott to coordinate the facilitation



Paula Deering, Carol McDonnell, & Lise Ellacott

of the Goderich Parkinson's Support Group.

These two women have connected on various levels from their passion for yoga and hiking, and their ability to understand what it means to have a loved one impacted by Parkinson's disease. Paula and Lise work collaboratively each month to facilitate the Parkinson's Support Group in the Goderich community. They have continued to engage PSSO clients each month, offering them a safe and inclusive space to connect with one another, all while providing various learning opportunities. Their volunteer involvement does not stop there. Paula and Lise have found unique ways to incorporate their individual passions into their volunteer experience with the organization.

Paula's passion for hiking and nature has always been something very important to her. She is an avid hiker and is inspired by working alongside other women with similar interests. In 2019, she generated an interest in the creation of a Hiking Group in her local community. They set out with a goal to hike the entirety of the Bruce Trail. Although this began as a leisure activity among friends, it soon turned into a unique fundraising opportunity for Parkinson's under the guidance of Paula. Paula and her team soon began to collect donations from individuals in their community who were interested in supporting their hiking initiative. It became very clear that there was an incredible amount of support. The group to date has hiked 580.8km of an 898.6km trail. With only 317.8km to go, the team has collected \$5,385 in pledges. Paula has shared that her overall goal is to raise \$5,000 to support the work of PSSO by 2024! Similar to Paula, Lise has shared her love and passion for yoga, in hopes of encouraging increased community engagement in the summer months. In the beautiful setting of Butterfly Park in Goderich, Ontario, Lise decided to facilitate weekly Yoga in the Park. This therapeutic opportunity allowed to take part in physical fitness but also to socialize with others in a recreational setting. Lise began to collect weekly donations from participants of the Yoga in the Park. After just two summers, Lise has raised \$3,174 in donations for PSSO!



2022 Fall Conference Volunteers - Daniel Kim, Hannah Lee, Samantha King, Leona Spasik, Tina George, & PSSO Staff Meagan Warwick

Conference Volunteers

This year PSSO hosted our Fall Regional Conference in Kitchener, Ontario on Saturday, October 21, 2022. This day was full of great presentations by key-note speakers, resources provided by event sponsors, meaningful interaction with clients and care partners, along with the wonderful volunteer team that supported PSSO on the day of the event! The volunteer team brought such enthusiasm and were so eager to support in any way they could. From welcoming clients and sponsors to facilitating the question period, these volunteers were “champions” of this event in every sense of the word. A big thank you goes out to the fabulous volunteers that helped in creating a safe and inclusive space for all, we are so thankful for your volunteer involvement.

Mailing Volunteers

There are several large-scale mailings that occur over the duration of the year at PSSO that wouldn't be possible without the support of our hardworking volunteer team. Volunteers dedicate their time to visiting the office space in London to coordinate all of the tedious details in preparing for the mailing. This team of individuals is such an integral part of the organization and we want to sincerely give them a shout out to say thank you for everything you do and continue to do for PSSO.



In-Office Mailing Support Volunteers - Gary Dallner, Neil Tenney, Dianne Belfour-Barnett & Wayne McManus

Pickleball and Parkinson's Disease: Janet's Story

Pickleball is one of the fastest-growing sports nationwide. As a result, courts have been popping up in community centres across the country, with many municipalities jumping on the trend. Some communities are even adding lines to tennis courts so either tennis or pickleball can be played on the same surface. Pickleball is played on a badminton-sized court with oversized ping-pong-type paddles, a plastic whiffle ball, and tennis-like rules. Pickleball is a great sport for those living with Parkinson's. It is a low-impact sport that helps keep you mobile and active, improves balance and hand-eye coordination, and is just plain fun!



When I asked tournament organizer Vicki Carrothers about how she came up with the idea of hosting the Pickleball for Parkinson's tournament, she said, "The idea came to me on a walk, when I was thinking about how I could help my sister and brother, who both suffer from Parkinson's, and how I could make a difference. I have been playing for nine years, have organized fundraising tournaments in the past and put 2 and 2 together." Her sister, Janet Noad, who was diagnosed with Parkinson's disease a few years ago, was thrilled at the idea. Vicki contacted Bernie Dunn, a fellow member of the London Pickleball Club, and together they began preparations for the tournament.

Janet has been connected to PSSO since her diagnosis when she was sent an information package with resources on how to access help. After being diagnosed, she was comforted by speaking with her brother Terry, who told her, "Parkinson's is not a death sentence." Janet tells me, "It is not a walk in the park either, but there are things you can do to alleviate the symptoms and live your best life." Since then, she has joined her local Rock Steady Boxing Program, and cannot say enough good things about it. She mentions, "Not only is it an excellent workout, but it is also a social gathering with people who are facing the same issues as I am."

More recently, Janet volunteered at the Oxford Walk for Parkinson's with her daughter and granddaughter and has come on board as a support group facilitator. Janet notes, "I highly recommend going to the support group meetings to meet other people who are facing the same or similar issues. You can learn a lot from each other."

Janet has always loved sports – she played baseball for many years, and now enjoys golf and pickleball. She plays pickleball twice a week with her group of friends.

Tournament details

Date: Saturday, May 6, 2023

Location:

The Flight Executive Centre, 2066
Dorchester Rd, Dorchester, ON
N0L 1G2

How to Register: Email
pickleballforparkinsons@gmail.com
or call Vicki at (519) 281-4625.



Janet adds, "They know I have limitations and they respect that and make me feel part of the team." Sometimes Janet gets so caught up in the action that she forgets she even has Parkinson's!

The Pickleball for Parkinson's tournament, taking place this May in Dorchester, will bring 65 players together, with the goal of raising funds and awareness for Parkinson's. Players will be divided into four teams of 16 players, and games will be timed to make sure everyone has a chance to play. Spectators are encouraged to come out and cheer on the players. Vicki mentions that pickleball is a social game with a strong camaraderie amongst its players. She concludes, "We will all come together and donate our time and money, and hopefully make even the slightest difference in the lives of people that suffer from Parkinson's disease."



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.

Will you help find the cure?

Kevin found out he had Parkinson's in his mid-60's. His symptoms were mild, but being a single person, he was not sure where to turn to answer the many questions he had about the disease, and how it might progress. Luckily, he was referred by his physician to Parkinson Society Southwestern Ontario (PSSO), where he found a welcoming community to help him feel more comfortable with the symptoms he started to encounter, and the feelings that he was having trouble expressing. Through interaction with other PSSO clients in his local Rock Steady Boxing program, online Support Groups, and by participating in Louder Clearer, he gained a better understanding of what might await him moving forward on his Parkinson's journey. The more he participated, the more he realized how important these programs were to his long-term physical, mental and emotional health.

As Kevin starts to plan his future (one that now includes a PD diagnosis), he wants to make sure that others who follow him will have access to the same services and programs which he found helpful in those first days, weeks and months following his diagnosis. In consultation with his extended family, his lawyer and the team at PSSO, Kevin has decided to make PSSO a beneficiary of one of his life insurance policies when he eventually passes. By leaving a gift for PSSO in his will, he will not only ensure that money is available to continue programming, but also his estate will receive a tax benefit to offset income taxes.

If you are interested in making a gift like Kevin's, reach out to either Mark (ext. 205) or Shelley (ext. 201) at PSSO, and they can help guide you in making a lasting gift. Kevin's legacy will have a long-term benefit to those with PD who come after him. Maybe your gift will be the one that helps us find the cure!

THANK YOU TO OUR FUNDERS



**Community Engagement and
Volunteer Coordinator Program**

**Dancing with Parkinson's
Program - London**

**Dancing with Parkinson's
Program - Oxford County**

In Memoriam

*We offer our sympathy to the families whose loved ones have passed away
between July 1, 2022 and December 31, 2022.*

Arlene Adams
Dianne Ahrens
Rob Alder
Steve Anderson
Kathleen Antaya
Bob Arrand
Tom Bannister
Bonnie Bellamy
Milton Bellamy
Beverly Bereza
Robert Berge
Michael Berrie
Jim Betteridge
Wayne Beuermann
Henry Bilik
Janet Boudrie
Eleanor Bradley
Helen Burger
Brian Burgess
Eleanor Calder
Sandra Campbell
Thomas Campbell
Joaquim Canhoto
Jack Carson
Francesco Cinelli
Marilyn Clarida
John Cook
David Couttie
William Cox
Pauline Cressman
Charles Croft
Patrick Dale
Norma Davidson
Howard Dayman
Mary De Baere
Clara Dehens

Dorothy DeKeyser
George Deschamps
Audrey Desrocher
Leroy Dettman
Agostino Dinunzio
Gloria Donald
Stan Duke
Harold Dynna
Sheila Edgar
Mike Evans
Lloyd Fair
Vince Farrow
Ernst Fast
Mike Findlay
Barbara Flood
Ron Forrest
Louis Francoeur
William Gard
Ernie Gignac
Jeremy Gilchrist
Ruth Hallman
John Halpenny
Virginia Halpenny
Mollie Hart
Wayne Harvey
Donna Hatten
Edith Herold
Linton Herron
Georgina Hill
Allan Hood
Patricia Howard
Dorothy Hyslop
Fred Jacklin
Ted Jacobs
George Jennings
Carol Jones

Don Keffer
Jean Kiers
Jill Labadie
Joe Lanoue
Eugene Lefebvre
Barb Linton
Bevan Loughheed
John Luttrell
William Lynch
Jim MacDonald
Guy Mackenzie
Wilfred MacLeod
Jeffery Mann
Luella Manners
Carl Marquette
Muriel Martin
Felice Masciotra
Glen Mateff
Bonnie Matthews
Tom Matthews
Murray McArter
Brian McBeth
John Wayne McKenzie
Bill McLean
Fred McLellan
Murdock McLeod
Virgil McNabb
Doug McQuaid
Ronald Meyer
Bob Miller
Everek Monk
Richard Moon
Carl Moore
Dave Morden
Katherine Morrow
Mari Movacich

Louise Mulcaster
David Nurton
Joe Oliveira
Angela Orlando
Pauline Ostrowercha
Gene Ouellette
Doug Outerson
Diana Paterson
Jack Paulley
Patricia Pawluk
Marc Penberthy
Audrey Pitts
Maria Pizzuti
Bryan Plant
JoAnne Plante
Graham Price
Harriet Pritchard
Gerrie Quarrie
Will Racki
William Rea
Leslie Reading
Ross Rieger
Linda Rigole
James Roache
Wilfred Rock
Jeff Roestenberg
John Rondelez
Brad Russell
Emmanuel Sambrano
Francis Saul
Gerald Schen
Robert Schihl
Wolfgang Schulze
Alice Schut
Rick Schwarzer
Giovanni Scoleri

Kayoko Shimpō
Ian Shouldice
Dave Simpson
Margaret Slade
John Sluis
Glenn Slusarchuk
Gary Smith
Gustaaf Soetmans
Ronald Spalding
Brian Stevens
John Strickland
Nancy Sumner
Joseph Szucs
Eric Tattersdale
James Taylor
Don Thede
Ilene Thompson
James Thompson
Cathy Tredenick
Mary Van De Wyncel
Charles Van Horne
Thelma VanGorkum
Judith Ann Varty
June Verbruggen
Lisa Voll
Larry Walker
Robert Wands
Elizabeth Webber
Stephen Williams
Robert Williamson
Margaret Willis
Paul Wing
David Yalden
Arnold Zantingh
Zlatko Zlatkov

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.

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