

# THE PARKINSON'S UPDATE

WINTER/SPRING 2024  
**ISSUE 79**

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# FROM THE CEO'S DESK

## Bringing Hope to Southwestern Ontario

Hope is an expectation and desire for a certain thing to happen. Hope also means to cherish a desire with anticipation.

Parkinson Society Southwestern Ontario's (PSSO) desire has always been to provide "Hope Close to Home" no matter where you reside in the southwestern Ontario community.

Thanks to you, we had an amazing 2023. We experienced a record setting year for Walk for Parkinson's raising over \$540,000! This is the first time in our organization's history that we have exceeded \$500,000. If you joined our walk – thank you for taking part and raising awareness and funds. We launched an exciting awareness campaign for Parkinson's Awareness Month called, "More Than You Can See". The goal of this campaign was to help educate the public that Parkinson's is more than a tremor and affects more than the person diagnosed. Finally, we had a fantastic turnout of over 230 people attending our Fall Regional Parkinson's Conference.

In 2024, our hope is to extend our reach throughout southwestern Ontario to all those affected by Parkinson's so that no one has to experience their Parkinson's journey alone.

We recently introduced our new Community Engagement Coordinator's (CEC), who are working throughout four main regions in our area, and we are excited to see the hope this will bring through programs and services, close to home.

As we head into spring, you will have the opportunity to attend a Living Well Conference in a community near you. There will be local workshops throughout the year and a monthly webinar series you can access online for free.

For carepartners, we will offer two workshops, one in the spring, the other in the fall. These workshops will have guest speakers who truly understand the role of carepartners and their needs. You will have the opportunity for connection by meeting some new friends, who are experiencing the same challenges as you, and learn ideas of what has worked for others.

We will continue to provide support groups you have all come to enjoy so much, supported by your local CEC.

These are exciting times for PSSO, shaping the direction of our organization, while we support our niche market, those living with Parkinson's in Southwestern Ontario.

Thanks for being part of our family.

*Shelley Rivard*

Shelley Rivard, CEO



Shelley Rivard

## 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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Dennis & Anne Beneteau



## I HAVE PARKINSON'S BUT PARKINSON'S DOESN'T HAVE ME

Article Written By: Anne Beneteau

This year we celebrated 45 years of marriage. Sustaining joy has been a life-time pursuit for us. Dennis's diagnosis of Parkinson's disease in the spring of 2013, at the age of 59, was one of life's challenges that sought to steal our joy...

Dennis has a sense of humour and a tender heart for others. Once, he considered becoming a comedian, but the closest he came was during years of weekly meetings with crazy activities that attracted young people, while sharing with their lives. Eventually, he moved into different pursuits, but he did not lose his ability to create one-liners!

Since his diagnosis, PD has gradually taken hold. Vision challenges cause him to see things that are not there. Blood pressure swings cause uncertainty. Flawed thinking causes confusion. Distress often shows up. We started losing our joy.

Concerned, I read to find ways to combat this shift. I discovered that his increasing dementia might benefit from reminiscing about the past. So I decided to pursue some storytelling of his childhood.

I began with a story I had heard that his family chuckled about - one with underwear elastic around the edges of a pie he baked. I asked him to recall more details so that I could write out his story. He

didn't remember much. I persisted about his kitchen, his yard and surroundings where he grew up. Soon, I began to create maps of his home, neighbourhood and community. His memories began to appear and take shape.

Our story of pie baking was our first. After many questions and drafts, he declared, "That's pretty much how it happened!". Then came a light-hearted laugh! The story had pushed away the gloom!

We hung the pie story on a hook outside his room. Staff members read the story on their break, enjoying a light moment in their routine and a new connection with Dennis. They returned with their own stories of adventures. We laughed at their exploits!

Today, we brighten the day with reading, or creating, one of the many stories that are collecting on the hook outside of his room. He recalls the rhythm and flow as the adventure unfolds. Cares disappear as we once again reach into the fun of his childhood along the banks of the river with family and friends, lost in the humour of found memories. He chuckles.

Yes, Dennis has Parkinson's, but it does not have us.

You can learn more about these stories at [giggle-stories.com](http://giggle-stories.com)

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.

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🐦 [ParkinsonSWO](https://www.parkinsonswo.org)





# CELEBRATING THE 2023 WALK FOR PARKINSON'S



On September 9<sup>th</sup> and 10<sup>th</sup>, Walk for Parkinson's events returned across southwestern Ontario and featured entertainment, food, prizes, and more! Participants gathered in some of the region's most beautiful parks and trails to walk and raise awareness for Parkinson's disease.

Across the region, from Owen Sound to Windsor, 1,600 participants and 193 volunteers 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!

These events would not be possible without the support of our amazing volunteer committee members, who worked tirelessly to organize and promote each walk. Thank you to all of our day-of event volunteers who made each walk run smoothly.

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.

WE ARE EXCITED TO ANNOUNCE THAT THIS IS THE **HIGHEST AMOUNT EVER RAISED FOR WALK FOR PARKINSON'S,**  
**OVER \$540,000!**

Mark your calendars for the 2024 Walk for Parkinson's, taking place on **September 7<sup>th</sup> and 8<sup>th</sup>**. We look forward to engaging with volunteers in April to begin the planning process for each event. Stay involved throughout the year by volunteering to sit on a local walk committee, starting your fundraising early, or thinking about who will be on your walk team this year.

Thank you again to everyone for making this possible. Your continued support provides hope for those living with Parkinson's and their families. Remember... every dollar raised through Walk for Parkinson's goes towards programs and services that benefit Parkinson's clients throughout southwestern Ontario. See you on **September 7<sup>th</sup> and 8<sup>th</sup>!**

## 2023 TOP WALKERS

1. Bill Schafer .....\$28,270
2. Clare Poechman.....\$18,314
3. Scott Dunbar .....\$12,318
4. Christine Scheer .....\$12,244
5. Grant Bourner .....\$9,139
6. Stuart Selby .....\$7,630
7. Rob Ecclestone .....\$7,263
8. Don Sararas .....\$7,037
9. Chris Evans .....\$6,649
10. Shane Curry .....\$5,133

# 2023 WALK for Parkinson's Sponsors



Bluewater Power, Carson Cleaners, Commonwealth Financial, Compass Minerals, Dixon Automotive, Elmwood & District, Chamber of Commerce, Ford Keast LLP, JASLO Properties, JMR Electric Ltd, John Ernewein Ltd, Karn's Roofing, KWIC Internet, Matchett Financial Services, MEDA Limited, Modern Staffing, Neuphysio Rehabilitation, Prime Time Chariot Inc, SpringTide Holdings, Tim Hortons, Town of Goderich, Triumph Tools, Troy Life and Fire Safety, Unifor Local 2458, Wayforth LLP, Windsor Factory Supply



# HOPE IS CLOSE TO HOME

As an organization, Parkinson Society Southwestern Ontario (PSSO) has a vision of reaching every person impacted by Parkinson's disease in southwestern Ontario. We know that it is essential to have access and support close to home. In October 2023, PSSO welcomed four new staff to the team to help us accomplish this vision.

These four staff have brought a variety of skills, experiences and perspectives that will serve them well in their roles. As Community Engagement Coordinators, their goals are to provide personalized support to people living with Parkinson's disease and their carepartners. They are working on expanding the programs and services offered in their respective areas, building community connections, and fundraising to strengthen the capacity of our organization.



**Stephen (Steve) Owen** is serving in the **Central Region** including **Elgin & Middlesex, Perth, Oxford and Norfolk counties**.

Stephen has a diverse background that spans from years with Community Living, Restorative Justice, and Church Ministry to Continuing Education programming/provision. His rich and varied experiences have uniquely positioned him for his current role as the Community Engagement Coordinator PSSO.



**Heather Galloway** has a Master of Public Health from the University of Waterloo, and a Bachelor of Science in Neuroscience from the University of Guelph. Heather's passion and drive will serve her well as she supports the **North Region**. She joins the team serving the **Grey, Bruce and Huron County** communities.



**Robin Arnott** has spent over a decade working in the field of disability advocacy and support services. She has a degree in Disability Studies from Toronto Metropolitan University. Robin is a lifelong learner with a passion for creating community and connecting with marginalized groups. Robin is serving the **East Region**, which includes **Dufferin, Waterloo and Brant**.



**Samantha (Sam) Grant** graduated from the Social Service Worker program at St. Clair College in 2016, where she specialized in Parkinson's and Dementia Studies. After completing her studies, she was privileged to become a member of the Ontario College of Social Work and Social Service Work as a Registered Social Service Worker. Sam is serving the **West Region**. This area covers **Chatham-Kent, Lambton and Windsor-Essex**.



# A JOURNEY OF HOPE AND RESILIENCE ON THE PACIFIC CREST TRAIL

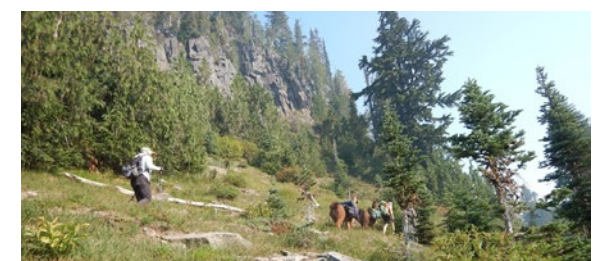
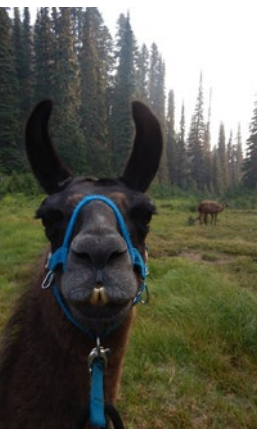
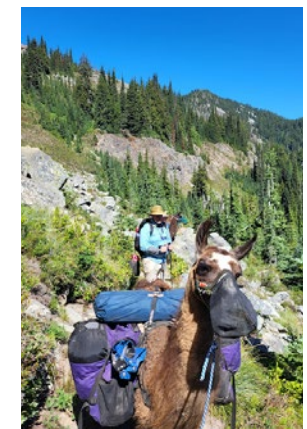
Article written by Darryl Walker

In August 2023, I embarked on an unforgettable journey with Pass-to-Pass, a non-profit organization that provides support and adventure for individuals battling Parkinson's disease. Along this trip, I took my support hiker and lifelong friend, Paul, and I, a Person with Parkinson's (PWP) diagnosed over six years ago. We went on a six-day backcountry hiking trip along a 45 km segment of the Pacific Crest Trail in Washington State. We were a group of 11, of which five members were PWP. Prior to this trip, we had only met each other on Zoom meetings. We also had four amazing llamas as part of the support team, lightening the load for the PWPs. Since this was a backcountry trip, all of the food and gear had to be carried for the duration of the hike.

On the morning of our first day, we were met at the trailhead by volunteers from Pass-to-Pass who welcomed us with snacks, drinks, and the llamas. After a final gear check, we were off. This first day was a grueling 10 km uphill trek through a majestic old-growth forest. The towering evergreen trees, some with diameters of up to 2 meters, created a surreal atmosphere.

I was tasked with working with the llamas. Their individual quirks and dynamics added a touch of humour and camaraderie to our trek. At the end of each day's journey, there was work that needed to be done before we could relax. The llamas required untacking and feeding, camp had to be set up, and water needed to be filtered from the lake for drinking. Once all the necessities were taken care of, we had our evening meal together as a group. Despite the physical challenges, the sense of accomplishment and camaraderie among our group grew stronger each day. It was amazing how rejuvenating it was to spend the six days with fellow PWP, sharing our struggles and helping each other accomplish a common goal.

The days blurred together as we were traversing challenging terrains, hiking along narrow rocky ridges, and crossing rivers. When we reached our final destination at Chinook Pass, a mix of emotions filled the air – a sense of achievement, gratitude for the organizers of the trip, and a newfound appreciation for the strength within us. Our adventure was more than a hike; it was a testament to the power of community, resilience, and the transformative impact of organizations like Pass-to-Pass. I am forever grateful for this incredible journey and the bonds forged along the trail.





EXPERT SPOTLIGHT

TOP TIPS FROM EXPERTS

What counselling support is available to me?

Living with Parkinson’s disease presents a unique set of challenges that can impact not only the individual affected, but also their loved ones. At Parkinson Society Southwestern Ontario, we recognize the pivotal role of counselling in enhancing the quality of life for individuals and families affected by Parkinson’s disease. Through our partnership with King’s College, our counselling student placements are dedicated to providing accessible and personalized support rooted in their education as these students have the intended purpose of mutual learning. Whether in individual or couples counselling, you will collaboratively explore coping strategies to facilitate emotional resilience and promote a sense of empowerment using a strengths-based approach. Counselling can be in-person, via Zoom, or over the phone.



Michelle has accomplished her degree in Psychology and is currently pursuing a degree in Social Work. She has extensive experience in volunteering with adults, children, and adolescents in mental health and education. Michelle has made significant contributions to King’s University College by being the president of the Social Work Student Association and founding the “Social Workers of Tomorrow Student Leadership Conference,” a platform that provides students with the leadership opportunity to present a Ted Talk-inspired presentation about their passions in Social Work. Known for her passion for learning and professional development, Michelle continues to explore new frontiers in the realm of Social Work, aiming to understand how to best support people from all walks of life.

How can I make sure that my home is safe for myself/loved ones?

Contact your local Home and Community Care Support Services (HCCSS) at 519.310.2222 and ask for an occupational therapist to visit your home for an in-home falls prevention and safety assessment. If you are part of a Family Health Team, you may also have free access to an occupational therapist to assess your home. There are multiple ways to make your home safe. A few tips include: decluttering your home and making sure you have clear wide pathways to walk, get rid of rugs/mats as they are trip hazards and increase your fall risk, add grab bars to your shower and toilet area to hold for safety, wear supportive shoes in the home that cover your toes and heels to reduce slip risks, ensure you have good lighting in your hallways and stairwells, use a nightlight to guide your path on late night trips to the bathroom and keep all tools, utensils in the kitchen between waist and shoulder height to reduce reaching, same with clothing in your bedroom.

Is there anything I can do to improve my balance?

Exercise is a key ingredient as we age, and certainly as you age with PD. Activities that promote strong legs and a strong core will help improve your balance. It’s important to work on your balance everyday and add it into a daily routine. Complete mini squats while standing at the counter washing dishes, work on proper posture while standing in the grocery store line up, practice standing on one foot while waiting for your tea to steep or toast to pop, practice walking with good posture while moving up and down your hallway, or holding your kitchen counter for support - then start walking with a high knee, or practice walking a straight line. Every minute spent practicing balance is better than none at all. Contact the local HCCSS for a physiotherapist or occupational therapist to come to your home for balance exercises, or reach out to the local VON 1.888.866.2273 to sign up for their free exercise programs for older adults. If you are savvy online, checkout [www.southwesthealthline.ca](http://www.southwesthealthline.ca) for exercise programs and falls prevention programs in your area.

Who do I call for access to mobility devices?

Your local pharmacy may have a rehabilitation department that can help you to obtain mobility devices. To add on, there should be mobility device stores in your area that can also help you. Contact 211 on your phone or online at [211Ontario.ca](http://211Ontario.ca) and ask for mobility device vendors in your area.



Tatum Bell has been an Occupational Therapist for 17 years. She has worked in a variety of healthcare settings with all age groups. She loves assisting people to live a happier healthier life and be the best they can be.

How do I maintain a balanced diet when I can only eat protein at certain times after taking my levodopa?

For people with PD, depending upon the levodopa and medication regimen, it is often recommended to eat protein foods at the end of the day to reduce dyskinesias throughout the day. This means that the balance distribution at breakfast and lunch meals would be 50% grains/starches and 50% vegetables and fruit.

The distribution of protein at the end of the day does not impact a person’s nutrition status overall. The thing to know is how much daily protein is needed for you. A personal calculation to use is a simple math equation of your best healthy weight in kilograms multiplied by 0.8. It is often a surprising amount to people and lower than they thought they needed. A rule of thumb is that most women need about 50 grams while men need 60 grams per day.

Breakfast and lunch, will contain grams of protein naturally found in some vegetables, in milk in soups, or cheese in sandwiches. This could account for approximately 10 grams of protein in the day and leave the rest for dinner. These low amounts of protein in the day will not be enough to cause competition for brain absorption, but will add to satiety and meal satisfaction.

See below for a guide on the amount of protein in foods for your evening meal choices.

- Animal, fish, seafood .....7 grams per ounce
- Small egg .....7 grams
- Legumes (beans, tofu, lentils).....4 grams per 4 ounces / 0.5 cup
- 1 cup of milk or 0.5 cup yogurt .....4 grams per serving
- Cheese.....7 grams per ounce

How can I get a balanced diet when I can’t safely cook for myself?

A balanced diet contains the food groups of grains/starches, vegetables and fruits, and protein foods. While a cooked meal is very satisfying, simple breakfasts and lunches made without a stove are nutritious too. Considering that the evening meal is often the main one and contains higher amounts of protein, this is most nutritious if it is home made by someone else and reheated in the microwave, or if a meal is delivered from a food delivery service that provides healthy food options with low fat and low salt choices.

If a person is not cooking for themselves, breakfasts of high fiber cold cereal with half cup of milk and a side of fruit is a nutritious start to the day. Lunch, without the use of a stove, can be a microwaved large bowl of vegetable soup with bread or high fiber crackers and a side of fruit.



Christine McIntosh is a clinician, nutrition counselor, and writer. Christine’s career crosses the spectrum of dietetics across all health domains, community nutrition project development, and research commitment to patient-centered care. Dr. McIntosh’s research and writing envision nutrition communications that fill the gap in a complicated food world.

# GIVE YOURSELF PERMISSION TO PRACTISE SELF-CARE

Article by Steven Owen, PSSO Community Engagement Coordinator based on interviews with Dr. Heather Bromley Little and Dr. Sarah Thompson

When was the last time you stopped to ask yourself the question: “How am I really doing?”

Self-care is an intentional and vital practice to maintain one’s physical and mental health. Being a carepartner for someone with Parkison’s disease can be extremely demanding. Therefore self-care is not a luxury, but a necessity.

Dr. Heather Bromley Little, a psychologist with a private practice in Woodstock, suggests that self-care begins with self-awareness. Once carepartners slow down and recognize their own internal state, it’s important to name it – “I’m exhausted”; “I’m noticing some feelings of resentment”; “I feel lonely”, etc.” When we recognize that we are finite and simply cannot accomplish everything that we’d like to do, we start to be aware of our limitations but also the strengths on which to focus, granting ourselves permission for self-care.”

Dr. Sarah Thompson is a Toronto-based clinical psychologist with over 20 years of field experience, as well as experience as a carepartner. She states, “We need to understand the importance of caring for one’s own mind and body as a necessity for being present and helpful to others.”

Bill Robson is a PSSO Support Group Facilitator who has lived experience as a carepartner to a family member with complex needs. Bill brings an extremely valuable perspective to our conversation about self-care. He emphasizes, “By making time for self-care, you are not being selfish; you are being smart.”

Dr. Bromley Little, Dr. Thompson and Bill Robson are all strong advocates for the needs of carepartners. They agree that carepartners tend to focus on their service to others and don’t always recognize the enormity of their roles. “It can benefit carepartners to speak aloud to

themselves about the demands they face” explains Dr. Bromley Little.

Dr. Bromley Little suggests that a person be aware of and nurture their physical, emotional, relational, spiritual, and intellectual health. A holistic approach enables them to provide attention and care from a healthy place.

She refers to the instructions given on a flight as a great reminder for carepartners “Should it become necessary, oxygen masks will deploy from above. Take and secure a mask on yourself first, then tend to the person beside you. It’s important that we note the order.”

Dr. Thompson likes to apply the analogy of a battery. “When our own battery runs down to zero, we have nothing left to give. Keeping our own battery charged lets us continue to give to others in rich and meaningful ways.”

While it may not always be easy, focusing on good nutrition and exercise is a wonderful way to ensure overall health. Dr Bromley Little states, “An adequate amount of sleep for themselves is proven to reduce anxiety and depression.”

Fostering relationships can safeguard the individuality of the carepartner. Carepartners should consider intentionally staying connected to people and groups that are life-giving to themselves.

Being attentive to one’s spiritual health, whatever that encompasses, is also key to a carepartner’s overall health. “We know that when we reconnect with nature by going for a walk, praying or meditating, it does wonders for the soul,” states Dr. Bromley Little. Bill also reflects by saying, “Set aside time each day to find peace within yourself in ways that suit you. Connect with your faith community or do some mindfulness activities.”



.....  
Dr. Heather Bromley Little is a clinical psychologist with 25 years of experience working with children, adolescents, and adults with a variety of mental health challenges. Her primary areas of practice include trauma recovery, life transitions, grief, and personal growth. She has a private practice in Woodstock, Ontario.

.....  
Dr. Sarah Thompson is a Clinical Psychologist, owner of the private practice Transforming Emotions, and adjunct faculty member at Toronto Metropolitan University Department of Psychology. With over 20 years of experience in the field, and as a past carepartner herself, she understands the importance of caring for one’s mind and body to be most present and helpful to others.

When a carepartner takes inventory of these elements, they embark on a journey towards holistic health. Drawing from personal experience, Dr. Thompson reflects, “Caregiving was one of the most challenging and most rewarding experiences of my life.” Remember that self-care is not a luxury, but a necessity.

“Knowing when to step back and take care of myself allowed me to stay connected to the person I loved.” - Dr. Thompson

## 6 WAYS TO PRACTISE SELF-CARE

Article by Robin Arnott, PSSO Community Engagement Coordinator

Tips from Carepartner, Volunteer and fellow person with Parkinson’s, Bill Robson

### Prioritize Your Own Health

You are in a complex situation and it’s natural to feel discouraged, angry, sad, and disappointed from time-to-time. Allow yourself as much compassion as you would your loved ones.

“Recognize when feeling discouraged begins to look like depression and seek help as soon as possible. PSSO can provide some resources and contacts for professional help if needed.” -Bill

### Find your team

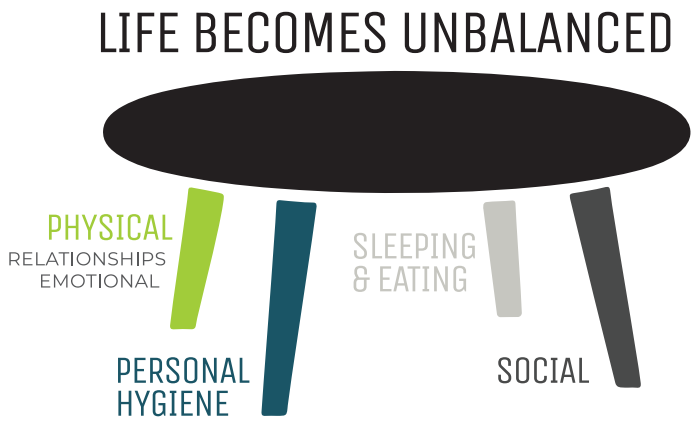
Connect with support groups or counselling services that are specifically designed for carepartners of individuals with Parkinson’s disease. Sharing your experiences with others who understand the challenges can be comforting and provide valuable insights.

### Educate Those Around You as You Educate Yourself

Understanding the condition, its symptoms, and potential challenges can help you anticipate needs and provide better care. Stay informed about new treatments and therapies that may benefit your loved one. Bill reminds us that “maintaining a good quality of life requires compromise, encouragement, and strength are needed from all family members.”

### Adjust your Routine

Creating a predictable daily routine can reduce stress and anxiety, making it easier to manage daily tasks and activities. Bill’s strategy, for instance, includes scheduling medical appointments in the mornings to leave the afternoons open for socializing and leisure.



### Communicate Openly with Yourself and Others

Foster open communication with your loved ones and other family members involved in the care. Discuss concerns, share responsibilities, and make decisions collaboratively. Clear communication can help prevent misunderstandings and ensure that everyone is on the same page regarding the care plan. Dr. Bromley Little emphasizes the importance of recognizing and naming our struggles to ourselves as this step is essential to identifying what type of self-care we need.

### Nurture your Personal Interests

Reading a book on a subject that acquires further or new knowledge, becoming involved in a new hobby, dusting off an instrument, and learning a new piece of music builds new neural pathways. This stretches one’s abilities and contributes to intellectual health.

“Find new activities that you can enjoy together to remain close, without Parkinson’s always being the topic.”- Bill



# PD, COGNITION AND YOU

Although we generally think of Parkinson’s disease (PD) as a movement disorder, there are other issues that develop and evolve over time. Changes in cognitive functioning may occur in approximately 15-25% of those newly diagnosed with PD<sup>1</sup>, and 80% of patients with PD experience cognitive changes 20 years post-diagnosis<sup>2</sup>. Given the impact of cognitive changes on your ability to function in daily life, cognition is a topic worth considering when visiting the Doctor.

## What’s normal, what’s not, and what can I expect?

Often, when people notice some change in their thinking skills, the immediate assumption is that it is a memory problem; however, more careful testing reveals that the underlying issues may have to do with other aspects of complex thinking. PD typically impacts the brain networks responsible for switching between tasks and reasoning (i.e., “executive functions”), semantic knowledge, and visual perception<sup>1,2</sup>. The whole story is complex as there is a lot of variation across people, and your individual cognitive performance depends on other factors like your age, level of education, occupational history, medications, and co-morbid conditions.

## What can I do?

If you have concerns about any aspect of your cognition, you should discuss it with your family doctor or primary care professional, who can refer you for a neuropsychological assessment. Neuropsychological assessments are done by licensed psychologists who specialise in neuropsychology, the study of the brain and

cognition/behaviour, & consist of an in-depth look at your various thinking skills, such as your memory, attention, visual skills, language, and executive functioning. The process involves a review of your medical history, an interview with you and a family member, followed by several different tests that usually take a few hours to finish. The result is a comprehensive look at your cognitive strengths and weaknesses, which can be useful for

- 1) Establishing a baseline so you can track any changes over time.
- 2) Providing useful information to your doctor about potential treatment options such as neurosurgical interventions.
- 3) Informing you and your family about everyday tasks in which you would benefit from support and;
- 4) Planning for the future.

## Where can I go?

Unfortunately, neuropsychologists with expertise in PD and neurodegenerative disorders are usually tied to large university-affiliated hospitals, such as London Health Sciences Centre, Toronto Western Hospital, or Sunnybrook Health Sciences Centre, which may be challenging to access for many of us in southwestern Ontario. We need to improve access to specialist services closer to where people live. As one example, the University of Windsor has a psychology training clinic, where we provide reduced-cost neuropsychological assessments to the community.

Feel free to reach out to me for more information (Kristoffer.romero@uwindsor.ca).



Kristoffer Romero is an assistant professor in the Psychology department at the University of Windsor. As a neuropsychologist, he provides clinical supervision to PhD-level trainees in the clinical psychology program. His research spans a variety of topics such as metacognition, culture, and improving access to health care services. He grew up in Kitchener, completed his doctoral training in Toronto, and now calls Windsor home.

# ADAPTING TO THE AFTERMATH: POST-COVID REALITIES FOR PEOPLE WITH PARKINSON’S DISEASE

In the face of the unprecedented challenges posed by the COVID-19 pandemic, individuals living with Parkinson’s disease found themselves navigating a unique set of obstacles. As we collectively grappled through the evolving landscape of the pandemic, it became increasingly crucial to shed light on the distinct impact it has on this resilient community.

The pandemic introduced heightened levels of stress and uncertainty for individuals with Parkinson’s disease. Disruptions to routine, restricted access to medical facilities, and concerns about the virus’s potential impact on health continues to contribute to a sense of unease. Managing this uncertainty was paramount for both physical and mental well-being. Therefore, the post-COVID era introduces a nuanced landscape for individuals with Parkinson’s disease. Adapting to changed routines, addressing potential lingering health concerns, and re-establishing access to essential healthcare services became focal points in the ongoing journey towards a semblance of normalcy.

The post-COVID period presents an opportunity for reinvigorating physical and mental well-being. With restrictions easing, individuals with Parkinson’s can now engage in rehabilitative exercises, reconnect with support networks, and rebuild social connections that may have

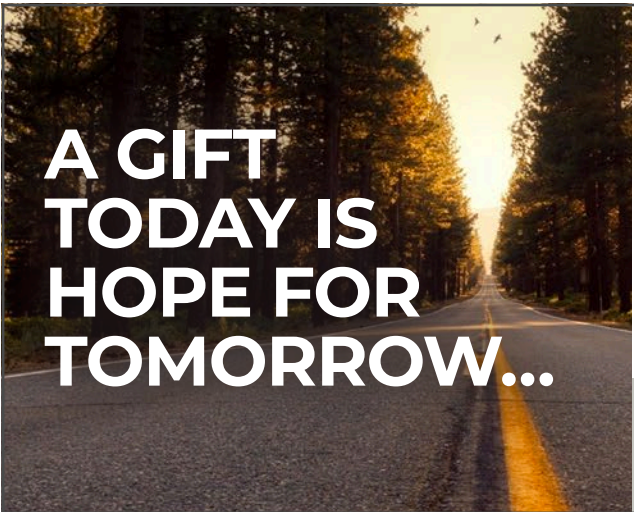
waned during the pandemic. This focus on holistic well-being is crucial for restoring and enhancing health overall. Community support continues to be a linchpin in the post-pandemic phase. Engaging with Parkinson Society Southwestern Ontario, participating in support groups, and fostering connections with virtual or in-person communities remains essential. The shared experiences of navigating through the challenges of the pandemic serve as a foundation for mutual understanding and support in the recovery process.

As the recovery journey unfolds, individuals with Parkinson’s can continue to leverage online resources, participate in webinars, and access educational materials tailored to their needs. These resources serve as valuable tools for ongoing support; offering information and strategies to cope with the evolving realities of post-pandemic life.

As we collectively transition into the aftermath of COVID-19, the resilience of the Parkinson’s community remains a beacon of inspiration. Through adaptability, support, and ongoing advocacy, individuals with Parkinson’s and their communities can embrace the challenges of the post-pandemic world, allowing them to foster health, strength, and continued resilience.



Michelle has accomplished her degree in Psychology and is currently pursuing a degree in Social Work. She has extensive experience in volunteering with adults, children, and adolescents in mental health and education. Michelle has made significant contributions to King’s University College by being the president of the Social Work Student Association and founding the “Social Workers of Tomorrow Student Leadership Conference,” a platform that provides students with the leadership opportunity to present a Ted Talk-inspired presentation about their passions in Social Work. Known for her passion for learning and professional development, Michelle continues to explore new frontiers in the realm of Social Work, aiming to understand how to best support people from all walks of life.



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.**



# ASSISTIVE DEVICES

## ADAPTIVE TOOLS & ASSISTIVE TECHNOLOGY, ADAPTIVE EQUIPMENT

Throughout your journey living with Parkinson’s disease (PD), you may find yourself experiencing new or different challenges with your mobility. The American College of Sports and Medicine (ACSM) releases guidelines and recommendations to stay active with physical activity throughout your day. As your journey with PD progresses, it is important to consult your healthcare team. This article will highlight some options for assistive devices, particularly related to performing activities of daily living (e.g., getting dressed, mealtime, bathing).

### What to consider before choosing an assistive device

- 1) Do you have a goal in mind with using an assistive device? Setting your purpose for using an assistive device may help narrow down options.
- 2) What options are available? The assistive device you are interested in may be offered by more than one company, and they may have different features provided as a result. For example, you may like the grip of one device better than another.
- 3) Try out the product. We are all made differently, so a device that works well for one person, may not be ideal for another person. Similar to articles of clothing, there is seldom a “one size fits all” approach. Test out a few devices to see what works best for you, functions the way you need it to, and fits best with your needs.
- 4) When you introduce a new assistive device into your daily routine, it can take time to learn how to use it. Be compassionate with yourself and get plenty of rest as you adjust.

### Technology - Robotic-based Devices

If you like technology or new gadgets, you may be interested in learning about robotic-based and social assistive robots. Socially assistive robots are often designed with Artificial Intelligence (AI).



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*Fallon Mitchell is a doctoral student in the Faculty of Human Kinetics at the University of Windsor. Awarded a prestigious Vanier Canada Graduate Scholarship, she is researching the physical and attitudinal barriers faced by vulnerable populations.*

These devices can help monitor your movements within an environment. For example, they can detect if you have fallen. They can also be informative, such as coaching you through exercises. There are other robotic-based devices that are physically assistive- this means they are designed to help you perform tasks such as carrying objects, standing up, and cleaning. Robotic-based assistive devices can also be helpful during rehabilitation or physical therapy programs, such as Robot-Assisted Gait Training (RAGT). This means they have been used in many research studies to offset lower extremity dyskinesia. However, robotic-based assistive devices are often costly, and may not be feasible for everyone.

### Mobility Aids

Common challenges individuals with PD experience include troubles with balance, gait (walking), and falling. Products that you may want to consider include straight canes with rubber tips, gait belts, or a laser cane. If you find that one of your more challenging actions is getting in and out of a vehicle, there are several transfer handle devices to choose from. A transfer handle is typically a portable and compact device that fits into the open door of a vehicle. When utilizing a transfer handle, you have assistance in pivoting your body and can transfer your weight more easily when getting in or out of a vehicle. There are also some riser devices that you can use to help transfer your weight and manage your balance when getting in and out of a chair.

### Bathing/Grooming Aids

Being able to maintain bathing and grooming practices are important steps in supporting your own independence. Many organizations offer support in determining what devices may be best for you in the washroom/bathroom. For example, a non-skid bath mat can be used by anyone to reduce the risk of slips and falls. There are ones that you

place inside the bottom of a tub or shower; they are meant to reduce slips and falls while in a wet environment. There are others that you place just outside of the tub or shower to assist with the transfer to a dry area when you may still be wet. You may also wish to install a shower chair/bench as it provides an area for rest. It is preferred if the installment is placed at another height level for a platform. More personal devices may include electric toothbrushes and razors, and long-handle brushes/ combs. Having an occupational therapist or registered kinesiologist come to your home for an environmental assessment is recommended.

### Dressing Aids

Certain PD symptoms can make performing tasks particularly frustrating. For example, a tremor or dyskinesia can make getting dressed a time-consuming process. Something that seemed like a normal part of your daily routine may seem more like a burden. Zipper rings is a product that can attach to the handle of your zipper – they make pulling up or down a zipper simpler by providing an easier grip or larger surface area. There are also different button aids or button hooks that help facilitate the movements needed to fasten a button. There are even devices to help put on your socks – such as the NC Medical Molded Sock Aid with Two Handles. Other tips or devices that may assist you when dressing include sitting down when dressing, using a footstool, trying magnetic fasteners, or having a shoehorn handy. It may also be recommended to perform some stretching exercises in order to warm up your muscles before getting dressed. Additionally, if you are experiencing more stiffness in one arm or leg in comparison to the other, it is



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*Dr. Paula M. van Wyk is an Associate Professor in the Faculty of Human Kinetics at the University of Windsor. Her research focuses on improving the quality of life of vulnerable populations, such as older adults and people with physical and developmental disabilities.*

advisable to dress the stiff side first (e.g., put the stiff arm in the shirt or jacket sleeve first).

### Mealtime

Meal preparation and eating can impact self-confidence and independence. This can range from difficulty raising a spoon to your mouth to being unable to see mashed potatoes on a white plate. Adaptive utensils (e.g. weighted, curved spoons) are one type of device that may assist with mealtime by making it easier to grasp and control utensils. Other devices may include rubber hand grips and non-slip placemats, which can help with stabilizing objects and reducing the strength needed to open items, like jars or bottles. Aprons with magnetic clasps and dishes with raised or rimmed edges of various colours are additional assistive devices that could help you with mealtime activities.

### Communication Aids

Several assistive devices can be used to help improve aspects of communication. As Parkinson’s progresses, changes in voice and projection occur. Voice amplifiers can be used to easily and automatically improve speech volume and clarity. Low-tech alternatives may be alphabet boards or picture charts that enable you to identify (e.g., spell out) words that you want to say. People with Parkinson’s experience many changing variables and it is important to remember that you have a voice and can get involved in your plan of care. As you are working with your healthcare team, remember that your input is crucial in the advancement of assistive devices. A registered kinesiologist or occupational therapist will be able to point you in the right direction.

## 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/](https://psso.ca/how-to-help/hero-of-hope/) or call **1-888-851-7376**.



# NUTRITION AND PARKINSON’S DISEASE

Food and Nutrition play an important role with Parkinson’s self management.

Good food is not just about what is on the plate, but also how it gets there, who makes it, how it is made, and the quality of it.

People with Parkinson’s are at an increased risk of poor nutrition because of the increase in metabolic demands of tremors, and a possible loss of olfactory senses such as taste and smell.

Muscular weakness or rigidity can also impact the swallow function. The ability to swallow is one of the commonly known challenges of Parkinsons and therefore the food texture needs to change too.

Did you know that the act of swallowing involves more than 300 nerves and muscles that are carefully coordinated from the mouth to the esophagus?

When nerves or muscles lose coordination and function, it leads to poor swallowing, called dysphagia. It is important for the food texture to match the ability to swallow because choking on food or aspiration of fluids can be life threatening. More often, a poor swallow allows food or fluid to enter into the lungs.

Dysphagia is a condition that is managed with varying the food and fluid textures. There are many products available to thicken fluids and many fluid products that can be bought already thickened. Dysphagia is managed the same way around the world. There are definitions of different levels of viscosity of fluids and textures of food. Dietitians are often trained in the assessment of dysphagia and can match the right textures to allow the swallow ability. It is the goal to provide the texture that is most like its original state. A change in texture can impact a person’s desire to eat the food, especially if it is too quick a change.

When a person needs a swallow assessment, either a trained dietitian or a speech language pathologist can do the assessment.

The MIND diet links two of the most studied diet patterns in medical research and is an acronym for Mediterranean-DASH Diet intervention for neurodegenerative delay.

It has been shown through many research studies that the diet supports brain function and also gut health. It is the optimal way to eat when living with Parkinson’s.

The food choices boost neuron function and high reduction of processed foods as sources of salt, trans saturated and saturated fat.

The way to arrange this type of eating is to portion half the plate with fruits and vegetables, a quarter with the protein portion, and a quarter with the high fiber energy food.

Carbohydrates also include cookies and cakes, which are clearly not included in this eating plan.

Let’s be realistic. Of course we eat treats and sweets at times, but they can be replaced with healthier options. Some sweets are high in inflammatory fats, salt, and sugar, it is best to wean them down as much as you can.

Just like mother used to say, “ Eat all of the wonderful plants that fill your plate”. These provide high amounts of fiber, and nutrients needed for cellular function and enzyme functions.

Nutrition elements like vitamins and minerals are key players at the cellular level in the body and brain.

Plants also have fiber, important for gastric motility and many are good sources of B vitamins, iron and magnesium.

The interest in these vitamins is their role in raising dopamine.

**Supplements that increase dopamine levels include:**

- Tyrosine is a natural amino acid and a precursor to dopamine. (Dopamine is made from tyrosine.)
- L-theanine is another precursor to dopamine.
- Vitamin D, B5 and B6. These vitamins are needed to make dopamine.
- Magnesium

A few studies have shown that insufficient magnesium corresponds to lower neuron function, but is not conclusive as a needed medicative supplement. Spinach, swiss chard, avocados, bananas, and potatoes are examples of fruits and veggies that are high in magnesium. Nuts are just as high, and also for chocolate lovers, 1 oz of 85% cocoa chocolate is high too, it has just as much as ½ cup of cooked spinach.

Supplementation is not conclusive for Parkinson’s, therefore a healthy diet is highly recommended. As there



are ongoing studies on minerals and vitamins, it is best to not take specific supplements of one thing over another, meaning a complex is preferred over one nutrient. It is important to advise your medical team if you take supplements because they can interplay with medications in their high dosages.

Fruits and vegetables are a very high source of antioxidants. From the word, you hear that they work against oxidants, also known as free radicals that cause reactivity at the cellular level that is not helpful. Free radicals in the nervous system induce pain, cause artery hardening in the cardiovascular system, induce cellular hardening and shrinkage in the brain, contributing to a slow brain decline.

Vitamins, such as D and C are effective antioxidant vitamins.

Vitamin D has been highly studied and dosages of at least 2000 UI are needed for general health for Canadians due to low sunshine exposure in the winter. Food sources of Vitamin D are not usually sufficient and is the one supplement that is required that does not impact medications.

Vegetables and fruits high in antioxidants include those of deep colour like dark greens and purples.

An important antioxidant is omega-3 essential fatty acids. These are found in plant oils and seafood. A diet with shellfish, fatty fish like salmon and trout, as well as white fish increases omega-3 naturally while omitting the unhealthier fats in red meat choices.

This brings us to the protein part of the healthy plate. Animal protein is an important source of B-12 that is especially important in the elderly population. A diet with chicken, eggs, along with fish or seafood, displaces red meat less often per week. Red meat is healthy when low fat cuts are chosen.

People with Parkinson’s know the relationship between protein and the medication family of levodopa and its cousins. Amino acids are the elements in protein that compete with levodopa at the cellular level for uptake into the brain. This means that the interplay between the protein foods and levodopa needs to be considered. The medication is often prescribed in dosages across the day to optimize thinking and function. It is best to take medications between meals, have lower protein meals through the day and keep the larger portion of protein to the dinner meal.

Finding your own way to manage the condition and your nutrition can feel challenging. However concentrating on one change for the week is the best way forward.

Many recipes can be found at [www.drchristinemcintosh.com/pssorecipes](http://www.drchristinemcintosh.com/pssorecipes)



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*Christine McIntosh is a clinician, nutrition counsellor, and writer. Christine’s career crosses the spectrum of dietetics across all health domains, community nutrition project development, and research commitment to patient-centered care. Dr. McIntosh’s research and writing envision nutrition communications that fill the gap in a complicated food world.*



# PREVENTING FALLS

A fall is when we lose our balance and end up on the ground or at a level, lower than where we first started. Many people are not aware that falls are the leading cause of emergency department visits, hospitalizations, and deaths from injuries in Canada. There are many risk factors that contribute to falling, including vision, strength, balance, and indoor or outdoor hazards. But, there is good news! Most falls are preventable and there are many things you can do to reduce your risk:

- Ensure your home is safe from hazards.
  - Indoor and outdoor stairs or steps are stable, clear of hazards and undamaged.
  - Remove clutter and scatter rugs to reduce tripping hazards.
- Ensure adequate lighting throughout the home.
- Work to build up your strength and balance.
  - Try your best to do 30 minutes or more of moderate to vigorous activity at least 5 times per week.
  - Incorporate strength and balance activities most days of the week, including gentle movement like yoga or tai chi.
  - Do what you enjoy! Dance, walk, bike, garden, or swim.

- Take medications as prescribed and work to mitigate side effects.
  - Use the Medscheck program; a free program to have your medications reviewed by your pharmacist. This program helps you to have a better understanding of your medications, how to get the most out of them, and how to use them best.
- Throughout winter, there are additional ideas you should consider to reduce the risk of falling.
  - Wear stable footwear with a non-slip sole or use ice grippers on your shoes.
  - Consider using walking poles or a cane for better stability.
  - Be aware of your surroundings; scan for ice, and uneven or changing surfaces.
  - If you find yourself on ice, move slowly and shuffle your feet.

A fall may cause you to lose confidence and impact your independence, so it's important to consider what might be a risk factor for you and do what you can to reduce your risk of experiencing a fall.

For more information on Fall Prevention visit [findingbalancealberta.ca](https://findingbalancealberta.ca).



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*Bailey Ressler is a long-term resident of Bruce County and has been a part of Grey Bruce Public Health since March of 2021. She enjoys being outdoors by spending time at the beach and time with her friends and family.*

# ELIGIBLE MEDICAL EXPENSES

At the time of diagnosis to the final stages of the disease, Parkinson's disease can cause financial burden to the patient and their loved ones. These unexpected costs can cause increased mental hardship. If your doctor has deemed that you qualify for disability and you paid for healthcare expenses at any point during a taxation year, you may be eligible to claim them as eligible medical expenses on lines 33099 and 33199 on your tax return.

You can claim only eligible medical expenses on your tax return if you, or your spouse or common-law partner:

- Paid for the medical expenses in any 12-month period ending in the taxation year
- Did not claim them in the previous year

Generally, you can claim all amounts paid even if they were not paid in Canada. An exhaustive list of eligible expenses can be found on the CRA website by researching "eligible medical expenses CRA" or by following the necessary prompts on the Canada.ca homepage.

A few examples of eligible expenses patients with Parkinson's may incur: bathroom aids (ex. grab bars, grips, rails), lift or transport equipment (power-operated), rehabilitative therapy, scooter, van/vehicle device, wheelchairs, and wheelchair carriers.

It is important to remember that although you do not need to directly send documents with your tax return you must retain them in case the CRA requests them. They include: Receipts, prescriptions, and a medical certificate of disability in writing. To help, the documents can be reviewed with a tax professional to

determine whether they are eligible or not.

You can claim eligible medical expenses in the following 2 areas:

- Line 33099 – Medical expenses for self, spouse or common-law partner, and your dependent children under 18
- Line 33199 – Allowable amount of medical expenses for other dependants

On Line 33099 of your tax return, enter the total amount that you or your spouse or common-law partner paid in the taxation year for eligible medical expenses. On the line below, enter the lesser of the following amounts:

- 3% of your net income (line 23600) or;
- \$2,479

Then, subtract the lesser amount above from line 33099 and populate it on the third line. Make sure to claim corresponding provincial/territorial tax credits on line 58689 of your provincial/territorial Form 428.

On line 33199 add up the total amount that you or your spouse or common-law partner paid in 2022 for eligible medical expenses and subtract from it the lesser of:

- 3% of your dependent's net income (line 23600) or;
- \$2,479

Enter the calculated amount above on line 33199. Similar to line 33099, make sure to claim corresponding provincial/territorial tax credits on line 58689 of your provincial/territorial Form 428.



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*Dean Weber is a Financial Planning and Analysis Manager, focusing on Business Finance. He graduated from Brock University with an Honours Bachelor Degree in Accounting, and has been a volunteer with PSSO since 2022. In his spare time, he enjoys golfing and reading.*



# RESEARCH CONDUCTED ON VIBRATING GLOVES AND THE BENEFIT TO THOSE LIVING WITH PARKINSON DISEASE

In December 2022, the Today Show featured a segment about a new clinical trial being completed in San Jose, California, USA. Through Stanford University, Dr. Peter Tass and his team are currently conducting the second step of their clinical study to establish the use of vibrating gloves and the mobility benefits to those living with Parkinson disease. This trial is using Vibrotactile Coordinated Reset Stimulation (vCR) sent from a main base unit to wires in the gloves that create an electrical impulse felt in a person's fingertips. The goal is to see an alleviation of motor ability symptoms and, eventually, to be used as a non-invasive treatment option for PD (rather than solely relying on DBS and medicinal interventions).

The trial began in 2014, when patients were asked to wear electrodes (that released 100-300 hertz of electrical current) on their head for 2 hours twice a day for 3 days. During the first round of clinical trials patients noticed an improvement in the distance they were able to walk before needing a rest as well as an overall improvement in their ADL capabilities. Based on the results from the study Dr. Tass and his team began looking at alternative methods of sending the impulses without direct contact to the head and the gloves were developed (as there are increased sensory nerves present in the fingertips). The gloves designed for round 2 trials are to be worn by patients for 2-4 hour intervals over the course of 3-6 months. They release a

sequence of 250 hertz electrical currents that lead to the de-synchronization of impulses.

The study is currently operating with 8 trial clients between the ages of 45-85 who have idiopathic PD (not caused by vascular deterioration/medication-induced). These individuals have been on a stable medication regimen for 1 month or longer (with no adjustments), experience a mobility increase of 30% or more when on medication (compared to their OFF Time) and are not taking any medications that affect their brain wave function.

Unfortunately, it has not been approved by the FDA as of the creation of this article. Further it has not been recommended for those who have a history of depression, dementia or ADHD (as changes to the brain can cause adverse reactions and thoughts). It can also have a negative effect on individuals who have had DBS, a traumatic brain injury, or epilepsy. Finally, as it is a clinical trial anyone who participated in another trial within 30 days of the commencement of this trial was not chosen (to prevent any counteractions).

As long as trials continue in a positive direction Dr. Tass will increase the number of patients in the study (to determine a larger scale of data) over the next year. At time of publication, it is predicted that FDA approval may be issued between the next 2-3 years.



## ALPHA SYNUCLEIN IN PARKINSON'S DISEASE

### Can we cure Parkinson's disease?

As we learn more about Parkinson's disease (PD), it is becoming clear that it is a complex disease that requires novel strategies to prevent its progression and to eventually discover curative therapies. As PD drug discovery efforts advance at a rapid pace, two major research areas could yield novel therapies in the coming years: the developing disease-modifying therapies and discovering therapies to prevent the toxic effects of a protein called alpha synuclein.

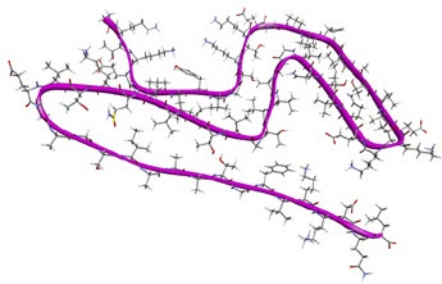


Diagram with a short explanation

### What is alpha synuclein and why is it considered a problem in PD?

Alpha synuclein is a protein found in the brain cells and is the major component of fibrillary aggregates, called Lewy bodies as seen in PD patients. This protein is one of the factors involved in causing PD. This protein can form clumps or aggregates, a process termed as "protein misfolding". These protein aggregates are toxic to dopamine -producing cells in the brain. They are also involved in triggering a number of pathological events, such as oxidative stress, mitochondrial dysfunction and neuroinflammation, all leading to degeneration of brain cells.

### How to prevent toxic effects of alpha synuclein aggregates?

Preventing the formation of alpha synuclein aggregates using novel agents is a highly promising approach to develop novel anti-PD therapies. Multiple preclinical and clinical trials are being conducted to discover novel therapies to prevent alpha synuclein - mediated toxicity. A recent study has demonstrated that an alpha synuclein aggregation inhibitor molecule minzasolmin was able to improve gait and balance, and to reduce brain inflammation in animal models. In early human trials, this drug candidate exhibited excellent safety profile when administered through oral route. Currently, the trials are ongoing in PD patients to evaluate its efficacy. This brings hope for curing PD in the near future.



Dr. Praveen Nekkar Rao is an Associate Professor at the School of Pharmacy, University of Waterloo. He is a Medicinal Chemist by training. His research group at the University of Waterloo is developing novel molecules as bioactive agents to study and treat brain diseases such as Alzheimer's disease, Parkinson's disease, Amyotrophic Lateral Sclerosis and other diseases.



Yusheng Zhao is a Ph.D. candidate at the School of Pharmacy, University of Waterloo under the supervision of Dr. Praveen Nekkar. His research focus spans rational drug design, medicinal and bioorganic chemistry, computational chemistry, and targeted brain drug delivery to treat neurodegenerative diseases. In the evolving landscape of pharmaceutical research, he is passionate about overcoming the challenges in the treatment of neurodegenerative diseases by integrating multidisciplinary approaches and innovative strategies.





# REFLECTING ON SEVERAL YEARS AS A VOLUNTEER

Article Written by Carolyn Young

I began my adventure as a volunteer with Parkinson Society Southwest Ontario about 7 years ago. Upon my retirement from teaching in both the elementary and secondary panels, I was recruited as a volunteer by the Canadian Cancer Society in Sarnia. After serving 9 years with them during my own cancer journey, I was ready to take on the role of Sarnia-Lambton Parkinson's Support Group Facilitator.

If I had to pinpoint the most memorable experience of my volunteer involvement, I would say it was the relationships forged these past seven years with others living with Parkinson's, their carepartners, PSSO staff and community contacts. I was given the opportunity to speak to professionals and interest groups in Sarnia-Lambton, thereby educating the population at large. I also attended monthly meetings with a network of health and community personnel.

Perhaps because I was on the Parkinson's journey myself, I felt immense empathy for each individual I met personally or spoke to over the telephone. My husband and I adopted a new "family" of sorts, wanting to care for them as best we could.

The annual Walk for Parkinson's is an event that my husband, Ron, family and friends look forward to because it brings "community" together not only as a fundraiser, but also as a show of support for loved ones dealing with the day-to-day challenges of this disease. The actual walk is a celebration, honouring those still with us and remembering those for whom the journey has ended. Last year, my husband and I along with our

**Carolyn, it is an absolute joy to have worked with you for several years. You brought such strength and light to the support group and all that you have done. Together, you and Ron have been wonderful advocates to the Sarnia community and people living with Parkinson's disease. As you continue your fight, please know we're always in your corner! We will miss having you be part of our volunteer community.**

— With kindness, the PSSO team.

family led the walk for Sarnia-Lambton – a memorable experience and such fun! PSSO utilizes the funds raised in such valuable ways, to provide a richer experience for both the person living with Parkinson's and carepartner alike.

Any opportunity to be involved with the staff and other volunteers such as in workshops, conferences, drop-ins at the office and socials are moments for recharging and getting a clearer perspective of the role. It has also been my privilege to work with a local PSSO volunteer, Dorothy Fyfe, who offers instruction in Parkinson's chair exercises at a local community centre and is the local Walk for Parkinson's organizer. Willing hearts and hands to share the load make all the difference in providing effective program opportunities.

It is very difficult to isolate experiences and memories when, collectively, volunteering with the PSSO has offered such an array of rewarding opportunities for learning and personal growth. Thank you!

# THANK YOU, THERESA DALY

Article Written by Guelph Parkinson's Support Group member, Bill Blackie

How do you say thank you to someone who works for ten years as a group facilitator?

That is the dilemma we face in adequately celebrating Theresa Daly.

After volunteering with PSSO for ten years as Facilitator of the Guelph Parkinson's support groups, Theresa plans to retire at the end of this year. In her role with us she has organized and facilitated well over 900 monthly support group meetings, one for folks living with PD and another for Carepartners.

Covid-19 presented real challenges, but undaunted Theresa's organizational skills ensured that meetings continued on Zoom. These sessions are an important element of meeting the social needs of the groups and we applaud her resourcefulness. The success of any group is that its size is maintained over time and Theresa's groups have not only thrived, they have also seen an increase from fourteen attendees to over seventy participants at present.

Theresa's passion for people, her empathetic understanding of the unique nature of Parkinson's, her recognition of the needs of both those living with PD and her focus on their carepartners has made her a fantastic facilitator. Her proven dedication has had a positive impact on attendees of the groups she has facilitated.

During her volunteer tenure, Theresa has ably contributed to and administered a wide range of projects,



most recently addressing the need for a PD Clinic at the Guelph General Hospital. Her approach involved building a team of people familiar with the needs of PD patients, which included Lloyd Longfield, Guelph's MP, representatives from the family health team as well as members of our Parkinson's support groups. Her efforts resulted in a commitment from the Guelph Family Health Team to strive toward funding as it becomes available.

Theresa, as you enter a new life chapter, we reflect on your immense contributions to the Parkinson's support groups in Guelph, amazed by the legacy your dedicated service has established.

The board and staff of PSSO and every person from our support groups wish you the very best and extend a huge **THANK YOU!**



# THANK YOU VOLUNTEERS FOR BUILDING AWARENESS AT HOME COUNTY MUSIC & ART FESTIVAL

From July 14 to 16, PSSO participated in the Home County Music & Art Festival at Victoria Park alongside other non-profits as part of the festival's community lane initiative. Volunteers were an integral part of PSSO's presence at this event. Volunteers helped to set up the PSSO booth and engaged with the public during the event by providing information about our programs, services, events and education initiatives. Volunteers also had fun by encouraging people to participate in our photo booth, and handing out PSSO themed colouring pages and bubbles.



# DO YOU WANT TO BECOME A HERO OF HOPE?

Parkinson Society Southwestern Ontario would not be able to provide the well-rounded community support that we do for people without the support of our members.

When an individual hears the words: “You have Parkinson’s”, they are often left with a limited amount of information and resources - waiting several months before being able to see a specialist who can answer their questions or address their concerns. There is a similar story for people who have known about their Parkinson’s diagnosis for years. If they are experiencing changes in symptoms or have questions about their medications, the wait for an appointment with a neurologist can be extremely difficult.

It is our goal to fill that gap and ensure that people living with Parkinson’s and their carepartners have access to educational resources, support groups, and programs within their communities that promote their well-being. When you join us as a Hero of Hope, you are helping us reach that goal.

Our members also support our investments in research. As an organization, we recognize that Parkinson’s is a complex disease that affects many individuals in different and unpredictable ways.

Symptoms appear differently in different people. Certain treatments may work well for one person, and be less effective for another. More research is key to understanding the intricacies of Parkinson’s disease, which is why we need your support. Through our Graduate Student Scholarship Program in partnership with Mitacs, we provided scholarships of \$20,000-\$25,000 to five young scientists examining different topics related to Parkinson’s disease. Knowing that efforts are being made to develop new therapies and learn more about Parkinson’s disease brings our community hope.

Not only does a strong membership allow us to continue to serve people living with Parkinson’s disease and their carepartners across southwestern Ontario, it also helps us build community connections. This helps with our requests for funding from governments, foundations, and corporations. We have added four new Community Engagement Coordinators to help expand the reach of our organization and increase local programming. We could not do any of this without the help of our generous members.

Join us as a Hero of Hope today!



# INVESTING IN HOPE



Parkinson Society Southwestern Ontario understands that hope comes in many forms. For us, hope means expanding our community programs, building more educational resources, and investing in research throughout southwestern Ontario.

Parkinson’s is the fastest growing neurological disease in the world. Although we know the cure for Parkinson’s hasn’t come yet, there are ways to bring comfort, hope, and support for people living with and impacted by Parkinson’s disease. A future full of hope is within reach, however, we won’t get there without the continued support of our generous donors.

Building a future of hope takes people who are willing to invest in the efforts of our organization. Investing in PSSO not only provides hope for the future but builds crucial support for people with Parkinson’s disease and their carepartners today.

We rely on the generous support of the community to help us provide programs, services, education, and to invest in research throughout southwestern Ontario. Donors,

“ Giving is not just about making a donation, it is about making a difference.”  
— Kathy Calvin

along with corporate community partners, make this work possible.

Major investments to PSSO allow us to increase our presence throughout local communities across southwestern Ontario. When we raise awareness, we gain stronger support, which allows more people to be served.

If you’re interested in making a donation and assisting in the wonderful work we do, please contact Shelley Rivard, CEO at shelley.rivard@pssso.ca or by calling 1.888.851.7376 ext. 201.

Your generosity will help us continue to bring Hope Close to Home for those living with Parkinson’s in your community. Thank you for your continued support!!

“ I volunteered and chaired the PSSO golf tournament for several years after my husband Bernie was first diagnosed with PD/dementia. I also joined the board for a few more years, but had to step away due to his increasing needs. This past spring, 5 years after losing my husband to PD, I volunteered at the Golf Tournament and then attended the AGM. I realized that I was missing the wonderful atmosphere that is fostered in this group to help many others living with PD and their families. So, I joined again! Please join me in donating your time, energy, and funds to an amazing grass-roots organization that is PSSO. ”

— Beverley Zaifman, PSSO Board Member, Major Donor & Volunteer



IN MEMORIAM

We offer our sympathy to the families whose loved ones have passed away between July 1<sup>st</sup>, 2023 and December 1<sup>st</sup>, 2024.

- Jimmy Agathos

Nadia Amadio

Stanley Antoszko

Allan Arthur

Marjorie Atkin

Thomas Awad

Dorothy Badregon

Patricia Baldwin

Terry Barker

Peter Bene

George Bennett

Edwin Blake

Margaret Blake

Albert Bollenbach

Bill Bradley

Terry Briggs

Ivy Brown-Johnson

Louise Bruckler

Herb Burdett

Stanley Cernanec

Olive Chambers

Joyce Chandler

Keith Charlton

David Chute

Jim Collins

Brent Connelly

Steven Conway

Bruce Cook

Carole Cooper

Jim Cox

Joseph Cromwell

Dario Cucinelli

Duncan Davidson

Lois Davitt

Michael Devine

Nicola Di Salvo

Lorenza DiLeonardo

Anna Dunlop
- Jules Dupuis

Marilyn Ferguson

Gary Ferrier

Helen Finlayson

Karl Giebat

Cheryl Glaab

Alan Gray

Robert Gray

Brian Grebow

Paul Grigg

Mitch Guthrie

Blythe Hamill

Raymond Hanson

Graham Hart

Herman Harvey

Terry Hill

John Holland

Barbara Hubbell

Twyla Jacklin

Marion Jaques

Bryan Jonas

Ron Kenney

Fred Koehlmann

Stephanie Krohn

Grant Ladell

Mary Lamb

Bert Lammers

Al Lander

Betty Learmouth

Bill Lester

Bryon Lillie

Allan Lindsay

Raymond Lizotte

Don Long

Rick Luckino

Johanna Lumley

Tom Lyttle

Paddy McArthur
- Colin McColgan

Jim McCoy

Robyn McCready

Ken McDougall

Walter McManus

Ronald McNeill

Antonietta Mescia

Irena Mieszcza

Lynda Mifflin

Alan Milner

Phyllis Nicholson

Vicki Nixon

Ross Noble

Stephen O'Connor

Emily Parent

James Parkinson

Edwin Patterson

Anna May Peach

Ellyn Peirson

Carl Pelkmans

Luzia Pereira

Heather Perrier

Edmund Petrauskas

Maggie Philipp

Brian Phillipo

Bill Phillips

Peter Plas

JoAnne Powers

Marion Pring

Kathleen Pye

Clara Ramsden

Elaine Ramsden

Grace Redekopp

Kevin Rice

Keith Richards

Lewis Roloson

Lou Romano

Bill Ryan
- Vinnie Ryan

Norma Sapsworth

Lois Sarll

Scott Schlaepfer

Anne Schwehr

Bruce Shannon

Gene Shelestynsky

Bill Shurish

Larry Simmons

Cliff Sjoblom

Tony Smeen

Delbert Smith

Dennis Stevens

Nina Grace Stewart

Cheryl Stockmann

Phil Strong

Linda Svenningsen

Gladys Swartz

Cecilia Tam

Heather Tinsley

Bert Van Lierop

Egbert Verbrugge

Ted Virgin

Doreen Walker

Brenda Ward

Judy Watson

Elfriede Wendland

Lynn Werkmeister

Freda Wesselson

Finley Williams

Slade Willis

Joseph Wood

Christine Wright

Tom Wright

Jim Yantz

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.

REFERENCES

Cognition, Parkinson's disease, and you - Page 12  
1. Biundo, R., Weis, L., & Antonini, A. (2016). Cognitive decline in Parkinson's disease: the complex picture. *Npj Parkinson's disease*, 2, 16018.  
2. Aarsland, D., et al., (2021). Parkinson disease-associated cognitive impairment. *Nature Reviews Disease Primers*, 7(47), 1-21.

PARKINSON'S IS...  
MORE THAN YOU  
CAN SEE

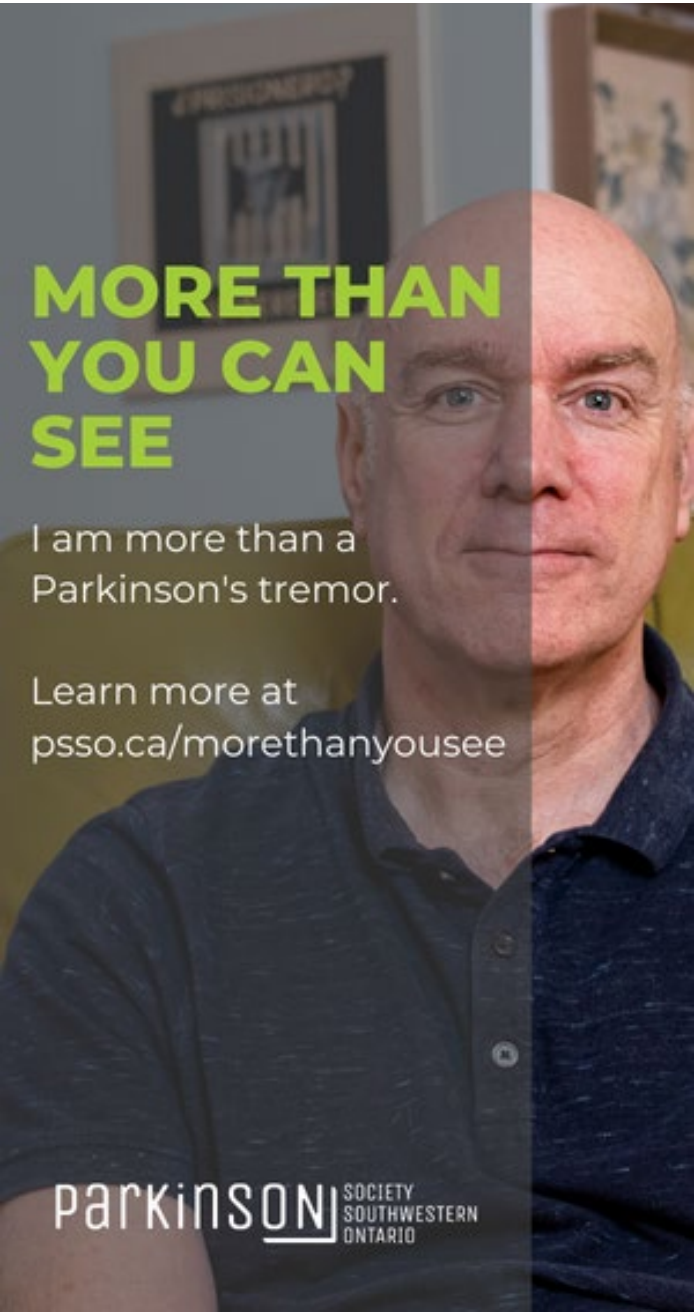
Parkinson's is the fastest growing neurological disease in the world and, arguably, one of the most misunderstood.

In April, we will once again launch our campaign "More Than You Can See", an awareness initiative to bring more understanding and consideration for people impacted by Parkinson's disease in our community.

We will be sharing four stories of people within our Parkinson's community, aiming to reflect the many voices across southwestern Ontario.

On World Parkinson's Day, we are joining with other Parkinson's disease organizations across Canada on the "Light it Up" initiative. We will be asking municipalities to light up their city halls and other major landmarks to recognize and support people with Parkinson's in their communities.

You can join us too. We will have opportunities for you to get involved and share your stories to help your community understand that Parkinson's is more than a tremor.. it's More Than You Can See.



WHO WILL YOU  
WALK FOR?

SAVE THE DATE  
SEPTEMBER 7<sup>TH</sup> & 8<sup>TH</sup>

Stay tuned for more details at [walkforpd.ca](http://walkforpd.ca)



# LIVING WELL

## WITH PARKINSON'S



**Join us for four mini conferences throughout southwestern Ontario this April!**

### LIVING WELL OWEN SOUND

**APRIL 2<sup>ND</sup>**

Harry Lumley Bayshore  
Community Centre,  
Bay Room

10:00am - 3:00pm

### LIVING WELL STRATFORD & AREA

**APRIL 12<sup>TH</sup>**

St. Mary's Golf &  
Country Club

10:00am - 3:00pm

### LIVING WELL FERGUS

**APRIL 16<sup>TH</sup>**

Fergus Legion

10:00am - 3:00pm

### LIVING WELL SARNIA

**APRIL 26<sup>TH</sup>**

Sunbridge Hotel &  
Event Centre

10:00am - 3:00pm

SPONSORED BY:

**abbvie**

To learn more about these educational opportunities and to register, visit [pssso.ca/events](https://pssso.ca/events)