A MAGAZINE FOR THE PARKINSON’S COMMUNITY OF SOUTHWESTERN ONTARIO

THE PARKINSON’S UPDATE

WINTER/SPRING 2020 · ISSUE 71

HOPE IS CLOSE TO HOME

Communication And Parkinson’s

Page 12

Botox Injections

Page 14

Accommodation in the Workplace

Page 18

Parkinson
Society Southwestern Ontario

MISSION STATEMENT

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

BOARD

Brad Richards (President)
Joseph Salamon (Treasurer)
Anthony Bender
Alysia Christiaen
Chris Curry
Tracy Dobbin
Dr. Jeff Holmes
Gary Pullam
Dr. Mandar Jog (Honorary)

STAFF

Shelley Rivard
CEO

Joanne Bernard
Manager of Administration

Kaitlin Garbutt
Community Development Coordinator - Brant, Norfolk, Waterloo, Perth, Haldimond

Jessica Halls
Manager, Fund Development

Lisa Nixon
Information and Referral Specialist

Tanya Park
Community Development Coordinator - London, Middlesex, Elgin, Oxford, Huron

Carley Schweitzer
Community Development Coordinator - Windsor-Essex, Chatham-Kent, Sarnia-Lambton

Vickie Thomas
Coordinator of Volunteer Development and Administration

Mark Womack
Community Development Coordinator - Grey Bruce

A special thanks to
@PRINT
for their contribution to this newsletter.

FROM THE CEO's DESK


Shelley Rivard

As we begin a new year, Parkinson Society Southwestern Ontario (PSSO) has made some exciting changes which I feel will have a positive impact throughout our local communities. Hope is close to **HOME**, where you can access the things you need to live better with Parkinson's.

We had an amazing 2019, thanks to you. We look forward to providing those same services and more. We have developed our **Community Development Program**. Through this program we want to make more programs and services available in a community close to **HOME**. Our staff are in the midst of planning our four Living Well Conferences: Your Physician, Your Pharmacist and You; as well as other educational workshops, partnerships and fundraisers.

Beginning this March - **Louder, Clearer: A Parkinson's Voice Training Program** is a program designed for those experiencing difficulty with speech, a symptom of their Parkinson's. PSSO will be providing group sessions led by Speech-Language Pathologists, an opportunity to learn and practise skills for louder, clearer speech. For those unable to attend a session, we will also be offering a Virtual/Online Program.

In partnership with King's College, we are in the midst of working on a **Counselling Program** for those in crisis. Once available, this program will provide counselling services with a Social Work Student.

As always, Lisa Nixon, Information & Referral Specialist, is available Monday, Tuesday and Thursday to speak to all clients regarding their needs and to connect them to resources in their local communities.

We are excited to see our **Getting Connected: Parkinson's Referral Program** grow, as physicians have begun to connect their patients with us. This program is designed to have individuals referred to PSSO by their physician at time of diagnosis.

Wherever **HOME** is for you, I look forward to seeing you at a conference, workshop, support group or one of our fundraising events, Hair Affair, Signatures: A Taste Test of London's and Waterloo Region's Best, Parkinson Golf Classic, WALK-IT for Parkinson's. You are never far from **HOME** with Parkinson Society Southwestern Ontario.


PSSO team (from left to right): Shelley Rivard, Jessica Halls, Vickie Thomas, Lisa Nixon, Tanya Park, Carley Schweitzer, Kaitlin Garbutt, Joanne Bernard and Mark Womack.

YOU ARE NEVER FAR FROM HOME WITH PARKINSON SOCIETY SOUTHWESTERN ONTARIO

HOPE IS CLOSE TO HOME

When you or someone you love is diagnosed with Parkinson's, the first question often asked is "where do I go?" Our answer is simple: **HOME**. Parkinson's Society Southwestern Ontario (PSSO) is that home. **HOME** for all those living with Parkinson's in Southwestern Ontario. **HOME** for you to find services, workshops and groups dedicated to growing support and the community around Parkinson's. **HOME** for education, advocacy and research initiatives built on spreading the awareness, care and support for Parkinson's. But most importantly **HOME** for **YOU.**

HOME FOR EDUCATION

- Resources in print and online at parkinsonsociety.ca
- Educational conferences, workshops and webinars
- In-services and presentations for health professionals
- Parkinson Education Program (PEP) for Community Caregivers online training at peponline.ca

HOME FOR SUPPORT

- Access to the toll-free information and referral line, 1-888-851-7376
- Provide customized information packages
- Link to Parkinson's-specific exercise programs
- Access to local community experts

HOME FOR ADVOCACY

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

HOME FOR RESEARCH

- Funding of local research initiatives including the Graduate Student Scholarship Program and the Brain Bank for Parkinson's
- Current information about Parkinson's research
- An important link to researchers and research opportunities in our community

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

Waterloo Office:
Wilfrid Laurier University Northdale Campus,
66 Hickory St., Waterloo, ON N2L 3J4.
Please call Kaitlin Garbutt at 1-888-851-7376
before visiting the office.

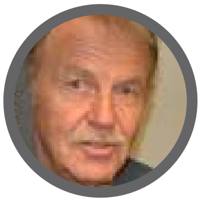
Although we make every effort to ensure that the information in The Parkinson's Update is accurate, we cannot take responsibility for any errors or omissions. Information is sometimes taken from letters to the editor, submissions from the Internet or other print material. We make an effort to acknowledge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

info@parkinsonsociety.ca **www.parkinsonsociety.ca** **ParkinsonSocietySWO** **ParkinsonSWO**

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

Al Lander's Story



Al Lander

A couple of years before retiring from a life of teaching, Al's students began complaining that his writing on the board wasn't clear enough to read. Over time, he started to notice a slight tremble in the fingers on his left hand and began having problems holding everyday objects like pens and small tools. And at age 63, while celebrating his recent retirement, Al received the diagnosis of Parkinson's.

Since then, the disease has progressed to his right hand. Some days the right hand is far worse than the left. Al is experiencing symptoms in his legs; his morning walk is of paramount importance to starting each day.

So is regular exercise. "Move!" states Al with passion. "Keep both your body and mind as active as possible." Al walks regularly and is looking into the positive results from Rock Steady Boxing, a program that has shown to increase quality of life for people with Parkinson's. Al has volunteered for Parkinson's research, was a volunteer driver with the Cancer Society, has enjoyed taking computer repair training, is an avid reader, and also states, "I won't let anyone feel sorry for me."

Al talks about how it is easy to feel sorry for yourself when dealing with Parkinson's, and also acknowledges that if you let that occur, you will become limited in what you can do physically.

The attitude and approach we can all adopt make a world of difference when dealing with personal challenges. He shares that he has had a good and healthy life, and also admits that what he now has, could be worse. There are crueller conditions to be diagnosed with and he is able to deal with most of the symptoms that come along.

Al is a bit disappointed that he can no longer play horseshoes; his body strength isn't what it once was, a common symptom with Parkinson's. And he stays away from ladders due to the dizziness that occurs, but he keeps busy with volunteering, learning new tasks, family and supportive friends who fondly address him as 'Shakey'.

AL SHARES HIS ADVICE TO THOSE NEW TO THIS JOURNEY:

- Join a Parkinson's support group. We all share and learn from the experience of others. We hear personal advice, stories and ideas on how to cope.
- Parkinson's appears in many different forms with varying symptoms that will progress over time. It can be disheartening to receive this diagnosis, but there are ways to minimize and control and cope with the symptoms.
- Keep up-to-date and informed. Educate yourself on what treatments and medications are available. Go to the Parkinson's conference – the information available is outstanding.
- Attitude is everything. Don't embrace a 'poor me' attitude, or that's what you will become. Get up, get going and get on with life.
- And most importantly – exercise constantly, to the best of your ability. Every day!

Having past experience with trades, he is also an advocate for personal protection equipment. "Over my career, I also taught Health and Safety. It can be a very unhealthy and unsafe trade if all the safety rules are not followed. One day I received a flyer on Parkinson's and welding. It stated that there was evidence to support a relationship between welding heavy metals and Early Onset Parkinson's. I included the flyer in my presentations, never once thinking that it might ever have an effect on me. Surprise! Was I ever wrong!"

The problem can occur when welding in close quarters without proper breathing protection. When Al was an apprentice, there was little concern for such things as breathing protection (everyone smoked back then). We know far more today about the potential dangers of not wearing the right protection. Al stresses, "Wear all personal protection available whatever your job! It's not worth taking the chance."

In closing, Al also offers, "Parkinson's is a dreadful disease but there are truly worse things in life. Take advantage of all the help that is out there. Stay informed, ask questions, have those tough conversations and keep up with all the advancements and changes – they are occurring regularly. Don't give up."

Written by Cheryl Losch, Volunteer, London

CAREPARTNER CORNER

Rebecca and Larry Gifford

It happens all the time, all over the world. Two people love each other. You build a relationship, a partnership, and ultimately share a commitment and a life. You grow and make plans, hopeful for the future. Somewhere in the back of your head, you know that something could happen that feels like the universe having a good chuckle at your expectations. It is easy to dismiss these thoughts as 'not right now' or 'perhaps when we're older.'

Then one day you hear a faint belly laugh. One of you is diagnosed with something frightening, and everything changes. Of course, everything shifts for the person with the disease, but the changes are just as profound for those closest to them.

Just as all families who are faced with a diagnosis do, we discovered a new path the day Larry was diagnosed with Parkinson's. As his partner and wife, when it appeared before me I took his hand so we could walk it together.

Sometimes it is joyful and beautiful - the opportunity to tell our story, to make a difference and to connect with a remarkable community; the opportunity to offer life-shaping lessons to our son; a chance to clarify, simplify and rebalance our life.

Sometimes it is sad or infuriating or frightening - grieving our pre-Parkinson's life, seeking balance in an ever-changing situation, adjusting to Larry's uneven physical and energetic capacities, shifting the balance of our parenting roles and facing endless uncertainty. Larry and I are re-examining and redefining our roles in our marriage, knowing we likely will need to do this again and again as the disease progresses. We are re-prioritizing our daily lives, while also discovering that often self-care means we cannot meet the expectations of those around us, including each other. And on and on.

Those who have been partners of people with Parkinson's for much longer than I have know that the above lists will get much longer before the food truck pulls away. For us and so many others, the growing pains are real.

We all know that everyone's journey is different. But as partners and most trusted caregivers, we have a front-row seat for our loved one's experience. We may not be experiencing the disease directly, but we have an important role. We are not just helpers, healers and emotional support. We are witnesses, observers.

We see their highs and lows, are inspired by their strength and humour, and are empathetic to their worries and grief. We are sitting beside them as they drive the roller coaster, an extra pair of eyes and ears on the track. This can be just as challenging, but also just as enlightening.

We can and are supporting them and choosing the spot beside our dear ones. Our journey is not easy, but it's full of all the thrills and lessons that a rich life brings.

Rebecca Gifford

Caregiver and wife

See Larry Gifford's podcasts about life with Parkinson's at: https://globalnews.ca/author/larry-gifford/

NEW RESOURCES
designed by caregivers and health care experts.

Caregiving Strategies: Providing Care and Support for a Senior Living with Frailty

Improve your skills, knowledge, and confidence as a family member or friend caregiver.

Support resilience, independence, and quality of life with

- Information
- Tools
- Strategies

Caregiving Strategies Topics

- Caring for the Caregiver
- Pain
- Staying Active
- Nutrition
- Bladder Health
- Medication Management
- Changes in thinking (Delirium)
- Social Engagement

RESOURCES AVAILABLE

- FREE online course
- Handbook
- Tools, tips and links to great resources

Get resources at
www.rgps.on.ca/caregiving-strategies

ASK THE EXPERT

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

CAN YOU BRIEFLY DESCRIBE WHAT WE KNOW ABOUT THE CAUSES OF PARKINSON'S?

The cause of Parkinson's disease is currently unknown. In most cases, patients will have no specific reason for why they have developed Parkinson's disease and currently we are not looking for such causative features in patients that we see in clinic. However, there are two known and identified risk possibilities for the development of Parkinson's disease but these are not specific for Parkinson's disease itself. Genetic predisposition can cause patients to have the Parkinsonian syndrome. Numerous genes have been identified but no single gene has been identified specifically to cause Parkinson's disease. The list of the genetic associations is long. In addition to this, environmental exposure to certain toxins, including excessive carbon monoxide exposure as an example, can also cause syndromes similar to Parkinson's disease. However, most patients have not had exposure to carbon monoxide, manganese or any other of these environmental toxins.

Therefore, it is possible that a person who has a form of genetic predisposition to Parkinson's disease from an inherited gene and then is exposed to an environmental toxin 'the so-called double hit hypothesis', ends up having a degenerative state in the brain that is then diagnosed with Parkinson's disease. However, as mentioned above, in routine clinical practise, we are unable to detect either of these types of associations.

With respect to Parkinson's disease, less than 10 percent of what we would call idiopathic or sporadic Parkinson's disease, has any associative genetic abnormality. Specific groups for example, Arabs or patients who have significant family history, or young onset patients with Parkinson's disease may be screened for these identified genes. The same is true in terms of environmental exposure. Certain groups such as welders or firefighters, who might be exposed to toxins in high quantities, may be screened for such exposure in their histories. However, this is not routinely done in the clinic for the sporadic Parkinson's disease patients.

Finally, there is a group of patients who have drug-induced Parkinsonism. Many psychiatric drugs and drugs that are used in the treatment of gastrointestinal symptoms (Stemetil) can also result in the appearance of Parkinsonism. Therefore, it is important that your physician knows the list of all medications including these drugs and others drugs that can result in drug-induced Parkinsonism. The important part here is that this Parkinsonism is potentially reversible if the drug is discontinued. However, I would not suggest discontinuing any medications unless discussed with the physicians in charge of your Parkinson's disease management in case there are significant repercussions with stopping such medications.

WHAT ARE THE CAUSES OF FESTINATION? ARE THERE ANY COUNTERACTING MEASURES THAT CAN BE TAKEN?

Festination is reduction in stride length of patients who suffer from Parkinson's disease. However, festination is not specific to Parkinson's disease and other conditions that look like Parkinson's disease. PSP (Progressive Supranuclear Palsy), MSA (Multiple Systems Atrophy) and even Alzheimer's disease can cause a reduction in stride length. Patients with reduction in stride length will also walk faster. Sometimes the reduction in stride length with increased speed of mobility is so severe that it results in freezing of gait where there is no mobility for a short period of time. This can happen spontaneously, in large spaces or in specific environments such as crowds, doorways or while turning on the spot.

The important issue with respect to festination is fall risk is higher with patients who have gait abnormality. This occurs if gait freezing is a result of a severe festination where the top part of the body will continue moving forward while the feet are glued to the ground. It is for this reason that adjustment of medications is very important to make sure that the drug therapy is optimized as festination can indeed respond in many cases to adjustment of medications. However, no specific medical treatment is available for this.

In the last little while, our laboratory has investigated surgical intervention using spinal cord stimulation in a very highly selected group of patients where severe freezing of gait and festination has responded. However, this treatment is still under significant scientific evaluation and is not available routinely.

As far as counteractive measures and strategies are concerned, stopping before entering a doorway or taking multiple steps while turning and doing it slowly can reduce freezing. Training programs including walking with a wider strength length consciously can also help. Over the years I have also asked patients to practise at home using a runner or mat with duct tape on the mat at a specific step length and practising walking on the duct tape to increase the stride length as part of training. Finally, gait aids such as the laser cane, or a regular cane where the patient specifically tries to step on the laser light that is projected on the floor or to kick the cane actively while trying to walk, can also help to increase the stride length and slow down the gait.

Specific physiotherapy for increasing the stride length and keeping the posture straight can also be tried. This can help reduce the fall risk as well with regards to the festination.

WHEN DOES ONE KNOW WHEN ONE IS HAVING ON OR OFF PERIODS?

The definition of an off period is related to the time when the symptoms that the patient has specifically for their Parkinson's disease return. It might be tremor in some people, stiffness in others, slowness or a combination of all these as motor symptoms or a reduction in mood, increase in anxiety as examples of non- motor symptoms that return. These symptoms will also be responsive to Parkinson's disease medications. When the medications are working, the patients will not experience disability from such symptoms. This is the on period. Therefore, recognizing the original symptoms that made the diagnosis of Parkinson's disease, or those symptoms that are responsive to the drug but fluctuate with the dosing of the medications, are the best gage of determining whether someone has on and off fluctuations. Unfortunately, as disease progression occurs, these fluctuations become unpredictable and this is the most difficult stage in recovering on and off periods. This is because at one point of the day, the symptoms might respond very well to the drug and the same symptoms don't respond at another time, or the next day at the same time. These fluctuations of on and off make it very hard for an individual or caregiver to recognize whether or not the patient is experiencing on/off fluctuations.

Discussion with the doctor is important with respect to determine whether these are on/off fluctuations. A mutual decision between the physician, the patient and the caregiver is important to make sure on/off fluctuations are indeed occurring. Medication adjustments may be required or even surgical intervention for such on/off fluctuations.

IS THE GENERIC BRAND OF SINEMET AS EFFECTIVE AS THE OFFICIAL BRAND NAME?

At this time, most patients are on generic Levodopa/Carbidopa combination and it is generally as effective as the general brand name. Over the years, a few of my patients have had a better response to the brand name Sinemet, but it is not easily justifiable at this time.

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

2019 REGIONAL PARKINSON CONFERENCE

AT BEST WESTERN LAMPLIGHTER INN ON OCTOBER 19,

PREMIER SPONSORS

ConnectCare

SpectrumCannabis

CHARTwell retirement residences

HearingLife

PRINCIPAL SPONSOR

Richmond Woods By Sifton

ASSOCIATE SPONSORS

epikura

sunovion

revera

THANK YOU TO ALL OF OUR SPEAKERS AND SPONSORS WHO MADE THIS EVENT POSSIBLE!

CONFERENCE SPEAKERS

Dr. Gloria Grace

Dr. Mandar Jog

Dave Levac

Dr. Scott Ryan

***Note:** Recordings from past conferences can be found by going to http://www.parkinsonsociety.ca/videos-and-audios/.*

SAVE THE DATE: The next Regional Parkinson's Conference is **October 17, 2020** at the Holiday Inn in Kitchener

COMMUNITY DEVELOPMENT PROGRAM

This past year, we completed our strategic planning process. It is important for us to hear the voices of each of you in our community and to make sure we are working on meeting the needs shared with us. One tangible way we could do this was to develop our Community Development Program.

In an effort to make more services and educational opportunities available in all the communities we serve, we introduced new members to our team. Each of our Community Development Coordinators (CDC's) brings a different skill set to our PSSO team and we are excited about their plans for 2020!

Each CDC will not only be working with support groups and planning April Awareness activities, but will also be working to provide local workshops, supporting the walks in the area and building local community partnerships.

CARLEY SCHWEITZER

Community Development Coordinator,
Windsor-Essex, Chatham-Kent, Sarnia-Lambton

Carley Schweitzer is the Community Development Coordinator for the Windsor-Essex, Chatham-Kent and Sarnia-Lambton areas. She is a graduate of the University of Windsor Communications and Media program and has been working in community radio for the past four years. Hired in October 2019, Carley has been busy settling in, meeting folks and booking some exciting upcoming events. The Chatham April Awareness workshop is taking place on April 22 at the John D. Bradley Centre with some exciting guest speakers. In Windsor, we are gearing up for an intriguing workshop at Ojibway Nature Centre focused on movement and mindfulness. The main speaker is Nancy Praill, a registered social worker who has been working in the field for over a decade, addressing concerns like depression, anxiety, obsessions, self-esteem, anger and marital therapy. Alongside Nancy is Coco, a yoga instructor who specializes in assisted yoga for people with mobility restrictions. We can't wait to see what they have to offer us. When Carley isn't working she can be seen biking along the Windsor riverfront or planning music for her weekly radio show. You can contact her at carley.schweitzer@parkinsonsociety.ca with any news, speaker requests or ideas.

TANYA PARK

Community Development Coordinator,
London, Middlesex, Elgin, Oxford, Huron

Tanya Park is our Community Development Coordinator for Huron, Elgin, London-Middlesex and Oxford counties, and is based out of the regional office in London. She joined us in July 2019 after working on City Council in London, as a PSW in both Long Term Care and Retirement homes, and as administrative manager for some local arts organizations. Throughout her career Tanya has lived and worked in many communities in Southwestern Ontario and feels at home almost anywhere. You can meet Tanya at the upcoming Living Well Conference in Zurich (at Hessenland) on April 14, at various support group meetings in her area or by sending her an email at tanya.park@parkinsonsociety.ca. In her spare time she, her husband and two children (Eva and Dylan) enjoy spending time at their trailer on Lake Huron.

MARK WOMACK

Community Development Coordinator,
Grey Bruce

Mark Womack is our Community Development Coordinator for Grey and Bruce counties. He is based out of his home near beautiful Sauble Beach and the shores of Lake Huron. He joined us in August 2019 after working for youth, healthcare and education non-profits for over 20 years in major urban and rural centres. Mark's focus has always been building strong relationships in the communities he's working with, while focusing on the needs of the organization. You can meet him at the April Awareness workshop on Tuesday, April 21 in Kincardine, at the various support group meetings in Grey Bruce or by contacting him at mark.womack@parkinsonsociety.ca. When not working for PSSO, Mark can be found walking his Basset hound, Archer, entertaining friends at his cottage, working on his home and cycling/hiking/kayaking around the Bruce peninsula.

KAITLIN GARBUTT

Community Development Coordinator,
Brant, Norfolk, Waterloo, Perth, Haldimand

Kaitlin Garbutt joined PSSO in May 2017. She originally started as our Programs and Services Coordinator. However, Kaitlin's role has now shifted to being a Community Development Coordinator for Waterloo region, Stratford, Brantford, Dunnville, Simcoe, Cambridge and Wellington-Dufferin. Kaitlin was born and raised in Waterloo and is passionate about community development and helping clients connect to useful resources within their communities. She received her B.A Gerontology at Laurentian University and is currently working towards completing her Masters of Health Administration (Community Care) at Ryerson University. In Kaitlin's free time, she enjoys yoga, Zumba, and running senior paint socials for people in her community! You can meet Kaitlin at the April Awareness workshop in Brantford on April 7 or at the Neurologist Information workshop on May 27 in Cambridge. You can also reach her at kaitlin.garbutt@parkinsonsociety.ca.

ADVANCES IN PARKINSON'S RESEARCH IN 2019 AT A GLANCE

The year 2019 was particularly fruitful for researchers studying Parkinson's. Whether it was basic research (to acquire new knowledge on the causes and mechanisms of the disease), or clinical research (directly with patients), 2019 brought many avenues of hope for the entire Parkinson's community.

WHY IS RESEARCH ON PARKINSON'S ADVANCING MORE SLOWLY THAN WE'D LIKE?

Before reviewing the major research advances, it is important to understand why Parkinson's research progresses so slowly. Here are a few explanations:

Each patient living with Parkinson's is different. It is therefore difficult to develop a drug that meets everyone's needs.

Lots of promising clinical research is underway. However, every year, numerous trials find treatments ineffective for several reasons:

- Parkinson's is not diagnosed based on a biomarker test (e.g., blood test, imaging). It is a difficult clinical diagnosis. Up to 20% of people enrolled in trials do not have classic Parkinson's. Therefore, these new treatments are not intended for them and the average response in the entire population participating in the study is negative.
- Parkinson's could be considered several diseases combined that present different symptoms and causes, depending on the individual. Thus, these new drugs may provoke good responses in certain patients while they are ineffective in others. Again, the average response in the population can be negative.
- Personalized medicine to provide individualized treatments to patients according to their needs seems particularly indicated for the treatment of Parkinson's. However, perfecting these treatments for small groups of patients is a lengthy process because it is difficult to recruit patients for clinical trials (there are not many). Furthermore, the pharmaceutical industry often is less incentivized to develop this type of treatment. It views them as unprofitable because they are intended for very small populations.
- Lastly, Parkinson's develops slowly in most cases. Therefore, assessing the effectiveness of new treatments takes a long time and requires recruiting many patients for studies. This is why many researchers are trying to find precise, quick and sensitive markers of the development of the disease.

Moreover, researchers have better identified these problems in recent years to accelerate the process of developing new drugs.

NEW THERAPEUTIC AVENUES ARE BEING DEVELOPED TO MANAGE THE SYMPTOMS OF THE DISEASE

In recent years, Parkinson's research has primarily focused on symptom management. This year was particularly promising in terms of research on drugs that will change the course of the disease.

SPECIFIC TARGETING OF THE ALPHA-SYNUCLEIN PROTEIN

Alpha-synuclein is a protein that is normally present in the neurons of the brain. The normal function of this protein is still unknown. However, we know that it plays a role in neuron death, particularly by taking an abnormal form, then aggregating into small clusters, Lewy bodies. Neurons are then unable to eliminate the cellular waste that ultimately causes the cell to die.

Accordingly, the new therapies have various targets: 1) reducing production of this protein, 2) preventing its replication in its abnormal form, and 3) facilitating its elimination.

Two types of treatment are currently in clinical testing: injection of immunoglobulins (antibodies manufactured in laboratory or by animals) that directly attack the protein aggregates. This is passive immunization, because the immune system is not directly involved. Five treatments are in effectiveness and safety testing. They are very promising.

In other avenues, a vaccine is being tested to assess if our own immune system is able to produce antibodies that will fight against alpha-synuclein clusters and cause them to disappear. This is active immunity.

Lastly, three oral drugs are currently being assessed for their ability to eliminate alpha-synuclein aggregates.

TARGETING LRRK2 AND GBA GENES

The LRRK2 and GBA genes are responsible for close to 10% of Parkinson's cases. Many research projects aim to understand how the activation of these genes produces the disease in entire families.

LRRK2

The pathological activation of the LRRK2 gene increases the risks of developing Parkinson's. It is the most common mutation in people with Parkinson's. This gene can be activated in any individual. It is moreover one of the genes activated by pesticides that can induce Parkinson's.

Once the gene is activated, it codes for the production of a LRKK2 protein. Therefore, treatments will aim at reducing the production of this protein or preventing its activity. Two drugs are in advanced research phases. These drugs are currently used in oncology, so their development time may be reduced because their safety has already been studied in the past.

GBA

A GBA mutation is found in 5% of people living with Parkinson's. It is historically the best-known mutation. This mutation results in the overproduction of a toxic substance. Several drugs are currently being tested to reduce the production of this substance. A gene therapy drug is even in development to directly repair the affected gene.

REUSE OF DRUGS AVAILABLE FOR OTHER DISEASES

These products are already available on the Canadian market and are approved to treat other diseases (e.g., cancer, diabetes). Moreover, their mechanisms of action suggest effectiveness on the symptoms or progress of Parkinson's.

These existing drugs present several advantages:

- Animal toxicity studies have already been conducted. This brings these drugs closer to their marketing for Parkinson's.
- Safety studies on healthy volunteers have already been conducted. Therefore, we can proceed directly with studies on volunteers with Parkinson's. On the other hand, these drugs must be tested correctly on the Parkinson's population. This can present several challenges.
- These drugs often were not intended to cross the blood-brain barrier. New dosing methods must therefore be found or the molecule must be modified.
- These drugs were not intended for an elderly population for which effective and especially safety doses are different. Therefore, studies must be repeated to find the appropriate dosage for people living with Parkinson's.
- These drugs have often been on the market long enough to become generic. This means that the patent has become public and therefore, the pharmaceutical industry does not have an interest in conducting new research on these molecules.

More than eight drugs are in Phase II and one major trial is in phase III. These drugs are mainly from cancerology and diabetology research, because they interact with the dopaminergic pathways that are deficient in Parkinson's.

HOW LONG CAN IT TAKE TO DEVELOP A DRUG?

Before they are made available on the Canadian market, drugs must go through several types of studies to prove their safety and effectiveness.

First, drugs will be tested on animals (toxicological studies), then on healthy volunteers (phase 1 study) to assess safety. Then, drugs are assessed on a limited number of sick people (phase II). These two phases can take between four and six years. If these tests are conclusive, then the drugs are studied on a greater number of individuals and all around the world. These are phase III trials that can also take four to six years.

Note: This article has been produced by, and reprinted with the permission of Parkinson Quebec.

COMMUNICATION AND PARKINSON'S

Written by Kerry King

Speaking loudly and clearly can become difficult for some individuals living with Parkinson's. The speaking changes are types of communication disorders. Speaking may be affected in a number of ways:

- Voice quality that is soft, breathy or hoarse when speaking
- Voice fades out or words trail off at the end of sentences
- Difficulty speaking loudly, or thinking you are speaking louder than you actually are
- Flat, monotone voice that lacks expression
- Slurred or mumbled words
- Changes to the rate and rhythm of speech (may be slow or rapid; may have irregular, fast bursts of speech; may have uncontrollable repetitions of words and phrases)
- Limited facial expression and stooped posture that affects ability to show emotion
- Difficulty with finding the right words in conversation

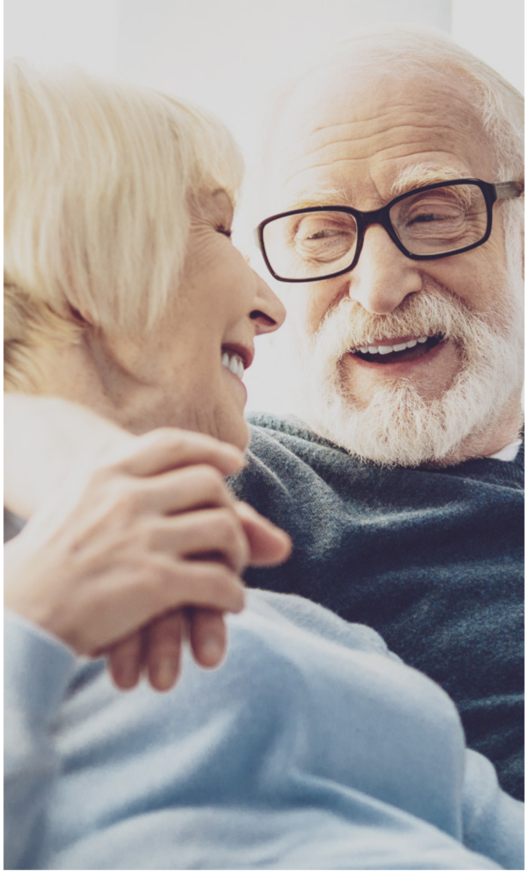
As a result, individuals with Parkinson's may find that they have to repeat themselves often to be heard properly. They may avoid loud or group settings, phone calls or making presentations. Over time, if left untreated, these difficulties can cause feelings of frustration and discouragement, reduce quality of life, limit social interactions and impact relationships with family and caregivers. Importantly, these difficulties can also affect an individual's dignity.

What should be done to help? According to the 2019 Canadian Guideline for Parkinson's Disease, it is recommended that individuals receive treatment from a specialist called a Speech-Language Pathologist (SLP, or speech therapist). SLPs are expertly trained healthcare professionals who work with an individual's healthcare team. SLPs evaluate, diagnose, manage and treat communication disorders, as well as swallowing disorders and issues with saliva control. They also counsel and educate family and caregivers to be able to manage the challenges.

There are many ways that SLPs help with communication disorders associated with Parkinson's. One effective way is by providing treatment in group settings (group therapy). In 2019, our team at Connect Speech Therapy had the privilege of hosting our inaugural Parkinson group therapy program with generous support from Parkinson Society Southwestern Ontario. Our weekly group training program gave participants an opportunity to evaluate their speaking volume and clarity, and identify the communication priorities in their life – their most important or difficult speaking scenarios. Participants practised exercises and techniques to improve vocal loudness and clarity when speaking. The techniques were based on fundamental, proven principles commonly used in speech therapy for Parkinson's. Each session was fun, practical and relevant to daily life. Caregivers, close friends and family members were invited to participate to learn effective strategies to help with communication in daily life.

By the end, participants were encouraged, enlightened and motivated. They commented that they were more confident to socialize or use the phone, could speak louder more easily, felt less frustrated, repeated themselves less often, could converse during noisy car rides and were better aware of how to manage the speaking challenges associated with Parkinson's. Although Parkinson's is a disease that progresses, it is possible to prolong functioning and improve quality of life with the help of an SLP.

Kerry King has been a speech-language pathologist (SLP) for nearly a decade. She is based in London, Ontario and enjoys working with clients of all ages at her full-service private practice, Connect Speech Therapy. She and her team have experience helping individuals who have communication or swallowing difficulties as a result of Parkinson's.



NEW

Louder, Clearer:

a Parkinson's Voice Training Program

Group sessions led by Speech-Language Pathologists to provide an opportunity for people with Parkinson's in Southwestern Ontario to learn and practice skills for louder, clearer speech in a relaxed and social atmosphere.

London
Tuesdays, 1:30 pm - 2:30 pm
March 3 - April 21, 2020
Advanced Medical Group,
230 Victoria St., London

Windsor
Tuesdays, 11:00 am - 12:00 pm
April 28 - June 16, 2020
Windsor YMCA,
3402 Grand Marais Rd. E., Windsor

Kitchener
Tuesdays & Thursdays,
4:30 pm - 5:30 pm
May 5 - May 28, 2020
Revera Briarfield Gardens Retirement Residence
1250 Weber St E., Kitchener

Virtual/Online
Mondays & Thursdays,
10:00 am - 11:00 am
April 20 - May 14, 2020

Cost: FREE! Register early as space is limited.
Email: info@parkinsonsociety.ca or Phone: 1-888-851-7376

Get LOUD! THERAPY
LIVE YOUR LIFE OUT LOUD

CONNECT
SPEECH THERAPY
communication | cognition | swallowing

GETTING CONNECTED

PARKINSON'S REFERRAL PROGRAM

Many people at time of diagnosis leave the doctor's office not hearing much of the information provided to them. All they have heard is the "you have Parkinson's" and don't retain much of what is said after that. Others may have been living with Parkinson's for several years and may have questions or need information between their doctor's appointments.

Getting Connected: Parkinson's Referral Program connects people with Parkinson's and their families to Parkinson Society Southwestern Ontario at the time of diagnosis or at any point in the disease's progression. The Parkinson's Referral Program aims to bridge the gap in the system and help clients (and support healthcare professionals) by connecting them to information, support and community resources.

Healthcare professionals can visit parkinsonsociety.ca for a fillable PDF of the Referral Form or have a Referral Package mailed to a medical office. For more information, call 1-888-851-7376 or email info@parkinsonsociety.ca.

Special thanks to UCB Canada for their generous support of this program.

MEMBERSHIP

HOPE IS CLOSE TO **HOME**. Be part of our Parkinson's family by becoming a member.

Our new membership program allows you the opportunity to increase access to supports for just $5/month.

$5/month can:

- remove a financial barrier for someone who can't afford to attend our annual conference. This helps them expand their knowledge and understanding of Parkinson's
- provide important information for eight people about their Parkinson's diagnosis through the Parkinson's Introductory Guide
- help eight new people join our Parkinson's family by receiving a welcoming information package

Be part of the solution in 2020 and impact the lives of people living with Parkinson's and their families in Southwestern Ontario. When we all work together, we can accomplish great things.

Contact Jessica Halls at jessica.halls@parkinsonssociety.ca or 1-888-851-7376.

BOTULIMYM TOXIN (BOTOX) INJECTIONS

Can They Help Your Symptoms of Parkinson's?

Written by Dr. Rebecca Gilbert

You most likely know that Botulinum toxin (more commonly referred to as Botox®, among other brand names) is used for cosmetic purposes to decrease wrinkles. Prior to being used in this way, Botulinum toxin was used for medical purposes to control abnormal movements. In the right hands, it can be a very effective measure to control a variety of problems related to PD.

WHAT IS BOTULINUM TOXIN?

Botulinum toxin is a substance produced by the bacteria Clostridium botulinum. Botulism is caused by the harmful effects of this toxin. If the toxin enters the bloodstream, it can spread throughout the body, causing widespread muscle weakness. In its full-blown form, botulism can cause difficulty with swallowing and breathing by causing weakness of the muscles that control these functions.

The good news is that decades ago, scientists learned how to isolate the toxin and harness its power for medical use, and it can be safely injected into particular muscles in order to decrease unwanted movements of those muscles.

HOW DOES BOTOX WORK?

Usually, a message gets transmitted from the nerve to the muscle by release of the chemical acetylcholine from the nerve endings. When Botulinum toxin is injected into a muscle, it gets taken up by the nerve endings that interface with the muscle, and interferes with the release of acetylcholine, thereby stopping communication between the nerve and the muscle. When this communication is decreased, the muscle is weakened and certain Parkinson's symptoms are lessened.

Conditions treated using botulinum toxin in Parkinson's disease

Dystonia – Dystonia refers to an involuntary twisting of a body part, which can be painful and can interfere with a person's desired movement. In PD, dystonia can be a motor symptom due to the disease, appearing first thing in the morning before taking medication, or as a dose of medication is wearing off. Alternatively, dystonia can be a side effect of Levodopa. A common dystonia in young onset PD involves toe curling or foot inversion (turning in). This dystonia often occurs only in particular circumstances such as while walking or running. Other dystonias involve frequent and persistent eye closure, known as blepharospasm, or neck turning, known as cervical dystonia. These can be associated with PD, but may also accompany other forms of parkinsonism such as Multiple System Atrophy or Progressive Supranuclear Palsy. Botulinum toxin injections, targeting the particular muscles that are moving excessively, can be effective in all these scenarios.

Tremor – Although Botulinum toxin is not commonly used for this purpose, there are case reports in the literature showing its effective use for the control of tremor.

Drooling – Likely due to the decreased swallowing rate of patients with PD, sialorrhea, or drooling, can be a feature of the disease. Drooling is not only an annoyance, but can result in significant embarrassment and social isolation. Botulinum toxin injections into the salivary glands can decrease production of saliva and thereby decrease drooling.

Urinary incontinence – This can be caused by a small, contracted bladder. Botulinum toxin injections into the bladder can relax the bladder thereby allowing for more normal urination. However, a known side effect of this treatment is urinary tract infection, so make sure you are aware of all the risks and benefits before starting the treatment. In addition, there are causes of urinary problems in PD that are not amenable to Botulinum toxin treatment, so you will need to discuss your particular situation with a urologist.

Botulinum toxin is used in various other medical settings such as dystonia that is not related to Parkinson's disease, migraine, and limb spasticity or stiffness after stroke.

DIFFERENT TYPES OF BOTULINUM TOXIN

There are eight different botulinum toxin species that occur in nature. However, there are only two that are produced commercially – Botulinum toxin A and B.

The commercially available products are:

- Botox® – Botulinum toxin A
- Dysport® – Botulinum toxin A
- Xeomin® – Botulinum toxin A which is produced free of complexing proteins
- Myobloc® – Botulinum toxin B

Each of the above agents are FDA approved for a slightly different list of clinical indications.

WHAT DOES BOTULINUM TOXIN TREATMENT FOR PARKINSON'S LOOK LIKE?

The effects of Botulinum toxin take hold about 3-10 days after the injections and last approximately three to four months, so the treatments typically need to be repeated on a regular basis. Although this means routine injections, it also means that Botulinum toxin injections do not have any permanent side effects. Some side effects may still occur with Botulinum toxin injections and the doctor who performs the procedure will review these with you. An advantage of using Botulinum toxin for the treatment of the conditions noted above, is that the toxin typically only impacts the areas into which it is injected, as opposed to oral medications which have a more widespread effect, and therefore more potential for side effects.

Side effects of using Botox

In general, side effects of Botulinum toxin can be due to over-weakening of the injected muscle. For example, if done on leg and foot muscle, it could interfere with walking.

Uncommonly, Botulinum toxin can diffuse to neighboring muscles and cause more widespread side effects. For example, injections to neck muscles could result in toxin diffusing locally to muscles used for swallowing and cause difficulty swallowing. Even less common are side effects due to travel of the toxin to more distant parts of the body via the bloodstream. For example, injections to any body part could theoretically result in difficulty swallowing or breathing if the toxin travels to these muscles. However, this is very rare and Botulinum toxin injections are typically very safe. The full risk profile for your particular situation needs to be discussed with the physician performing the injections.

There are typically no limitations after the injections and you can return immediately to your normal activities.

Although dermatologists often use Botulinum toxin for cosmetic purposes, only a neurologist is qualified to determine whether the injections can help with certain PD symptoms. If you are interested in investigating whether Botulinum toxin injections may help you, discuss this with your neurologist. If he/she feels that they may be helpful, but does not perform them, he/she can refer you to a neurologist who does.

TIPS AND TAKEAWAYS

- Botulinum toxin injections can help in the management of certain features of Parkinson's disease.
- If you think you have a symptom that can be treated with Botulinum toxin (dystonia, drooling, urinary incontinence), discuss it with your neurologist.
- There may be a role for Botulinum toxin injections in control of tremor, but this is less commonly done.

Note: This article has been produced by, and reprinted with the permission of the American Parkinson Disease Association. https://www.apdaparkinson.org/article/botox-treatment/

Dr. Gilbert received her MD degree at Weill Medical College of Cornell University in New York and her PhD in Cell Biology and Genetics at the Weill Graduate School of Medical Sciences. She then pursued Neurology Residency training as well as Movement Disorders Fellowship training at Columbia Presbyterian Medical Center. Prior to coming to APDA, she was an Associate Professor of Neurology at NYU Langone Medical Center. In this role, she saw movement disorder patients, initiated and directed the NYU Movement Disorders Fellowship, participated in clinical trials and other research initiatives for PD and lectured widely on the disease.

WHEN A LOVED ONE DIES

Written by Mary Bart

At a time of great grief, families (especially estate executors) are usually faced with the responsibilities of having to create an appropriate plan - one that allows them to make important and sometimes time-sensitive moral, legal and financial decisions.

DIRECTLY AFTER DEATH

- There is no panic to do anything immediately (unless the person’s organs are being donated).
- Only one master death certificate is issued and is used to register the death with the province.
- Funeral directors or providers will issue ‘proofs of death’ for estate purposes.

FIND THE WILL

- Find the original copy of your loved one’s will (required at every step of settling the estate).
- Look at power of attorney documents, driver’s license and funeral prearrangements.

PLANNING THE FUNERAL

- Will the body be embalmed? Will the casket be open or closed?
- Will the body be cremated? What is the plan for their ashes?
- What is the funeral budget? Have any expenses been prepaid? Who will pay?
- Will there be visitations before the funeral?
- Who will speak at the service? Will there be music? Who will be pallbearers?
- Will there be charitable donations? What about memorial cards?
- Will there be a reception with food?

NOTIFYING FAMILY, FRIENDS AND COMMUNITY

- Contact as many people as possible (death notices, social media, emails, phone).
- Ask for help from your family, friends and funeral home director.

THE RECEPTION

- Celebrations of life are very popular and can also be done at a later date.

THANK EVERYONE

THE FINAL RESTING PLACE

Purchase a cemetery plot, a headstone or space at a mausoleum for burial or buy an urn for cremation.

CLOSING DOWN AFFAIRS

- It is recommended that you work with a lawyer and an accountant to make things go as smoothly as possible. They can save you many hours of frustration and months of delays.

GET ORGANIZED

- Ask the funeral home or provincial government for at least 12 copies of the proof of death certificate (if death occurred outside Canada then you must get a death certificate from that country).
- Keep the original will. If you do not have the will or suspect that one was never drawn up, consult a lawyer on how to proceed.
- Create an inventory of all assets, including bank, brokerage, insurance, pensions and benefits accounts, titles and deeds to properties and vehicles (including RVs and boats), and details of furniture, jewellery, fur coats, stocks, art and so on.
- Make a list of the bills and account numbers for utilities, mortgages, loans, credit cards and property taxes.

Work through the list of tasks noted below. If you need assistance then an estate documentation company can help you to manage many of the jobs, excluding legal and accounting issues. This service may be of particular interest to those who are grieving and overwhelmed.

NOTIFY

- Service Canada, Canada Revenue Agency, Veterans Affairs and Elections Canada
- Financial institutions and insurance companies (car, home and life)
- Employer and pension providers
- Utility companies
- Religious, cultural or professional associations
- Canada Post (have mail forwarded to the executor)

CANCEL

- Government health insurance
- Driver's licence and passport
- Citizenship or permanent resident card
- Secure Certificate of Indian Status
- Newspapers and magazine subscriptions
- Memberships and credit cards
- Email, social media and online shopping accounts

INVESTIGATE

- If any survivor benefits will come from pensions or insurance policies (including from employers/unions), death, survivor or children benefits, Old Age Security, employment insurance, Veterans Affairs or the Canada Pension Plan
- What benefits you might be entitled to, according to whether you were married, in a common-law relationship or a dependant child of the deceased
- The correct time to close out bank and brokerage accounts (e.g., RRSPs, RIFs, disability savings plans, investments, savings/chequing, safety deposit boxes)

NOTE: your lawyer and accountant will be of great value here

SECURE OR MAKE ARRANGEMENTS

- The deceased's home and vehicles
- Furniture and belongings (rent temporary storage if more time is needed)

PAY

- Funeral expenses and all outstanding bills
- Any taxes that are owing (check with the Canada Revenue Agency)

As you can see, 'it takes a village' to properly respect funeral and burial/cremation wishes while also wrapping up the deceased's affairs. Delegate as much as possible to family members, funeral director, lawyer and accountant/tax preparer.

It is only by having a plan and a team in place that you will be able to start another critical process: your own grieving journey.

Mary Bart *is the chair of Caregiving Matters, an Internet-based charity that offers education and support to family caregivers. Go to https://www.caregiversolutions.ca/top-stories/when-a-loved-one-dies/ for the complete article.*

ACCOMMODATION IN THE WORKPLACE

Written by Jane Scholes

Disclosing a medical condition, like a Parkinson's diagnosis, triggers an employer's duty to accommodate an employee under human rights legislation. Knowing your employer's obligations and your rights is the first step to ensuring that the process goes smoothly.

If your employer is federally regulated (for example, banks), the key piece of legislation is the Canadian Human Rights Act, R.S.C. 1985, c. H-6. If your employer is provincially regulated (which is most employers), the key piece of legislation is the Ontario Human Rights Code, R.S.O. 1990, c. H.19.

Whether the Act or the Code applies, the basic consequence of the legislation, and the case law applying it, is the same: employers are required to accommodate an employee's disability. This is part of ensuring that an employee with a disability is treated equitably, and is not subject to discrimination. Discrimination based on disability is prohibited under both the Act and the Code.

ACCOMMODATIONS CAN INCLUDE:

- modifying your existing work duties
- creating a new role with new duties
- modifying your work schedule
- allowing you to take leave(s) as necessary and formulating appropriate return to work plans
- modifying how company policies and procedures apply to you

In order to accommodate you, your employer has to consider your restrictions on an individual basis. This will generally require documentation and information from a medical practitioner setting out your diagnosis and restrictions relevant to the workplace. Your provider may include, and differentiate between, requirements and recommendations, which can impact the content of the accommodations offered.

Accommodation must be a collaborative process, and it includes both substantive and procedural obligations for the employer. In short, this means that an employer cannot simply make assumptions or impose proposed accommodations. Your employer has a positive obligation to make reasonable inquiries, consult and work cooperatively with you and make reasonable good-faith efforts to come to a satisfactory accommodation plan. You can ask to involve a support person or advocate in this process. If you work in a unionized environment, your union representative is usually a good place to start.

While accommodations should be robust and must be appropriately tailored to your unique circumstance and limitations, there is a limit on an employer's duty to accommodate: the point of 'undue hardship.' How Courts and Tribunals apply this standard varies on a case-by-case basis, but, in general, the threshold is quite high. Mere inconvenience or some cost to the employer is not enough. It is up to the employer to establish and prove undue hardship.

If you disclose your Parkinson's diagnosis and are not given appropriate workplace accommodations, you may have a human rights claim. If you are not only not accommodated appropriately, but are terminated from your employment, you may also have a wrongful dismissal claim. The damages arising out of these types of cases can be significant.

If you or someone you know has questions or concerns about your rights in the employment setting, contact a lawyer specializing in employment law promptly and before taking next steps. An employment lawyer can help you determine your rights, negotiate with your employer and ultimately commence a claim, if warranted.

Lerners Lawyers has a team of highly skilled and qualified employment lawyers with significant experience in workplace accommodation matters. Jane Scholes is an Associate at Lerners. She practises primarily health law and labour and employment law, including human rights law matters.

THE GOAL OF TREATMENT - QUALITY OF LIFE

Written by Dr. Soania Mathur

Until there is a cure, it's all about quality of life.

Why treat the symptoms of Parkinson's or any other disease for that matter? Why initiate treatment at a particular time? What is our ultimate goal? The answer is very clear - it's all about quality of life.

Quality of life may be defined as the perceived quality of a person's daily life, including the physical, emotional and social aspects of life experience. And how that translates into real terms varies from person to person. What issues that need to be addressed in order to improve my quality of life will potentially differ from those issues that are a hindrance to you. For example, when I had a really busy day in my practise or when I worked in the urgent care, an extra 30 minutes or an hour of tremor-free time allowed me to function well and continue my clinical responsibilities. However for an elderly person, now retired, the most bothersome symptom may be constipation or anxiety which, if resolved, would result in greater enjoyment of life. And those parameters by which you judge your quality of life can change even during the course of the disease. Your needs and goals may change with time. Once I stopped working, I was no longer willing to suffer the side effects of the medication. Instead I tolerate the tremor, which under the current circumstances is less of an issue.

Quality of life truly is the primary end point that should motivate all decisions when it comes to our medical care.

Sometimes however the medical community falls into the trap of treating symptoms instead of the patient. As a physician I know this may happen inadvertently from time to time. Yes it is a positive result if a patient's tremor is less on a certain medication, but is it a successful outcome if that therapeutic intervention results in uncomfortable side effects or fails to address a totally unrelated symptom that is causing the majority of the disability in that patient's life? Is it enough to treat what we are used to considering the hallmark symptom of a disease? Rather should we place highest priority on the complaint affecting the patient the most, which, when improved, results in a noticeable improvement in the quality of day-to-day life?

Only you know how this disease is affecting your quality of life and what your goals are in terms of your life experience. Therefore, it is up to you to convey this information to your physician in an effort to reach those goals and optimize your quality of life. Any symptoms or combination of symptoms that interfere with those occupational, social and recreational interests that make you who you are, that give you pleasure and enjoyment, can be said to compromise your quality of life and must be addressed.

So in addition to the normal information on your symptoms, treatment effectiveness and side effects, you must also relay your general impression of how the manifestations of Parkinson's are impacting your life overall and which symptoms specifically interfere the most. Perhaps despite your tremor, you're functioning quite well and you don't want to risk the side effects of increasing your medication. Or maybe the tremor is so significant that it is compromising your ability to eat or your duties at work. Information on how your symptoms are interfering with your activities must be addressed by your medical team if you want to truly live well with Parkinson's disease.

Until the day we find a cure, as physicians and as patients, we need to concentrate on improving symptoms in order to optimize activities of daily living, recreational and occupational activities and interpersonal relationships, all those aspects that are so important in determining an individual's quality of life. Maintaining independence, increasing productivity and improving overall life experience must be our goal. It really is all about quality of life.

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

WALK-IT PARKINSON'S

CELEBRATING SUCCESS!

THANK YOU

TO EVERYONE WHO JOINED US TO MAKE **WALK-IT for Parkinson's** IN **2019** A **HUGE SUCCESS!**

LOCATION	AMOUNT RAISED
Brantford-Brant County	$16,807
Chatham-Kent	$8,832
Goderich	$15,623
Grand Bend	$26,225
London and District	$79,410
Owen Sound	$16,160
Port Elgin, Kincardine and Area	$22,514
Sarnia-Lambton	$52,955
South Grey Bruce and Hanover	$42,462
Stratford and Area	$32,757
Strathroy and Area	$10,447
Tillsonburg-Norfolk County	$6,394
Waterloo Region	$51,896
Wellington-Dufferin	$19,682
Windsor-Essex	$57,648
Woodstock-Ingersoll	$8,007
TOTAL	**$467,819**

2019 WALK-IT for Parkinson's Sponsors

REGIONAL SPONSORS

Kenmore Homes
A Legacy of Fine Homes Since 1955

CHARTWELL retirement residences

Assante Wealth Management and Ross Mitton
Be well-advised.

The Mufflerman
COMPLETE AUTO SERVICE

Connect Hearing
YOUR HEARING PROFESSIONALS

Belle River Wind

Armow Wind

Grand Renewable

North Kent

South Kent

PREMIER LOCAL SPONSORS

Dure Foods, McCormick Canada, RPA Enterprises Inc, Steeves & Rozema, Bluewater Power, Bill Brown Income Tax, CMR Insurance, Hunter Steel and Supply, KW Civitan Club, Newtex Cleaners, Toyota Motor Manufacturing Inc., Unifor 444

PRINCIPAL LOCAL SPONSORS

Gates Canada Inc., Kent & Essex Mutual Insurance Co., Exeter Lioness Club, Bluewater Office Equipment, Compass Minerals, L. H. Jenkins, The Dock's Restaurant, Town of Goderich, York Developments, HRT Insurance Consulting, WFS Ltd., General Dynamics, Unifor Local 88, Precision Home Medical, E. Hoffman Plastics Inc., Matchett Financial Services, Ontario Power Generation, T.A. Brown Funeral Home, Dr. D.G MacKay Dental, Rowland's Independent Grocer, The Queen's Bar and Grill, Tim Hortons - Port Elgin, Team DeCoppel Remax Land Exchange, Starlight Casino Point Edward, Enbridge Pipelines Inc., Unifor National, John Ernewein Limited, Karn's Roofing, Viking Cives Ltd., Elmwood & District Chamber of Commerce, The Co-operators, Dean Ribey-Agent, Carson Cleaners, Georgian Bay Cremation Services, Core Fuels Ltd., Hamstra Carpet One, Strathroy Mini Storage, Town & Country Mutual Insurance, Canadian Tire Strathroy, Boston Pizza (Tillsonburg), CBI Health, Unifor Local 2458, Season's Retirement Home Amherstburg, Season's Retirement Home Belle River, Season's Retirement Home La Salle

*For a list of top teams and walkers, go to **www.parkinsonsociety.ca**.*

COMMUNITY PARTNERSHIPS

- Brierwood Gardens – Booster Club (Brantford)
- Caesar's Windsor (Windsor)
- Canduct Industries Ltd (London)
- Chef on Call (Waterloo)
- Chorley & Bisset Employees Charitable Contributions (London)
- City Hall Charity Chest Fund (London)
- CUPE Local 107 Benefit Fund (London)
- Gourmet Emporium (Windsor)
- Great-West Life Assurance Company
- Hessenland Novemberfest (Zurich)
- IBM Canada Employees Charitable Fund
- Kerwood Bethesda UCW (Kerwood)
- Kitchener-Waterloo Civitan Club (Waterloo)
- Long Point Lioness Club (Port Rowan)
- Mount Forest Lions Club (Mount Forest)
- Order of the Eastern Star, Bethlehem Chapter 136 (London)
- Order of the Eastern Star Rundle Chapter 108
- Pelee Island Winery Golf Tournament (Pelee Island)
- Putt Fore Parkinson's (Cambridge)
- RBC Durham/Ayton (Durham)
- Sarnia Bluewater Chordsmen (Sarnia)
- Southwestern Ontario Lawn Tractor Racing Association (SOLTRA) (Belle River)

HONOURING LOVED ONES THROUGH DONATIONS

- Roy Bedford (Chatham)
- Sandra Campbell (Cambridge)
- Janine Currie (London)
- Roy DelCol (Windsor)
- Semih Demir (London) Wedding of Chhering & James
- Alicia Duval (Bolton) Wedding
- Gayle & Dwight Esler (Orono) Christmas
- Earl & Barbara French (Lucan) 50th Anniversary
- Harjit Garcha (London) 10 years of Service with Middlesex-London Health Unit
- Bob & Nancy Kett (Jarvis) 40th Anniversary
- Carol & Jerry McDonnell (Goderich) Art Exhibit Opening
- Lori Moore (London)
- Nancy & Al Oakley
- Shannon Reed (London) 10 years of Service with Middlesex-London Health Unit
- Elena and Mike Saffran (LaSalle) 60th Anniversary
- Debbie Sanders (Morpeth) Retirement
- Jack Sims (St. Thomas)
- Otto Weber (Mitchell)
- Fred Zylstra (St. Thomas)

MATCHING GIFTS

- Enbridge Gas – Matching Gifts Program (Chatham)

FOUNDATIONS

- PayPal Giving Fund Canada
- Sue and John Barnes Foundation
- Irene and Georgina Agnew Memorial Foundation

Members of the Sarnia Bluewater Chordsmen presented a cheque to Sarnia Parkinson's support group facilitator, Carolyn Young. The funds were earned from a recent Christmas concert.

HOLD YOUR OWN EVENT

A new year is upon us and you may be interested in supporting Parkinson Society Southwestern Ontario in new ways. How about planning your own community fundraising event?

Become a Champion for Parkinson's and raise funds to support Parkinson's services, education, research and to help build a strong advocacy campaign in Southwestern Ontario. Parkinson Society Southwestern Ontario can provide friendly support, as well as website and social media promotion.

From garage sales, birthday parties and barbecues to sports tournaments and car shows, no event is too big or too small. Take the lead, get creative, build awareness, raise funds … and don't forget to have fun!

Your actions have an impact – start planning your event today!

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

TECHNOLOGY MAKES IT EASY TO FUNDRAISE!

If planning and organizing isn't your thing, did you know you don't have to throw a party or come up with an amazing event idea to fundraise? It can be as simple as using online tools to let your friends and family know about the cause near and dear to you!

FACEBOOK

1. Login. 2. Go to create a post. 3. Within the options, click the three dots and choose 'support nonprofit' From here, you can follow the prompts – just make sure when choosing the nonprofit, you type Parkinson Society Southwestern Ontario and it will pop up! It's as easy as that! All funds raised will be deposited directly to PSSO from Facebook.

PAYPAL

Do you use paypal? We have a direct link to give!
paypal.com/ca/fundraiser/charity/3456581
You can share this link on your social media sites or send an email to friends and family.

Questions? Email info@parkinsonsociety.ca or call 1-888-851-7376.

PELEE ISLAND GOLF TOURNAMENT

In July 2019, hundreds gathered in support of Elena Saffran and the Saffran family. The inaugural Pelee Island Golf Tournament brought together golf and wine enthusiasts – but most importantly, colleagues, friends and family. The day started with a beautiful day of golf at Orchard View Golf Club. At the end of the day, everyone gathered at Pelee Island Winery for an evening of delicious BBQ and drinks!

It was clear that Elena and her husband Mike are dearly loved and admired by many. Stories shared around the table spoke volumes of how much they've done for their community – and how much their community wanted to give back to them.

Thanks to the hard work of Ron Swift, Chrystie Porrone and the amazing support of the winery, over $7,000 was raised to support people living with Parkinson's in Southwestern Ontario.

Events like this make a big difference in the lives of our Parkinson's family. Whether you want to host a small get-together with close friends or gather the community for a big event, all the funds raised help to provide essential support services, educational opportunities and ensure that Parkinson Society Southwestern Ontario can invest in research and bring awareness of Parkinson's in our local community.

Thank you Pelee Island Winery, Ron and Chrystie for all your work to support our Parkinson's family!

MORE THAN JUST A HAIRCUT

SUNDAY APRIL 26

10am - 2pm

Appointments will be made available mid-February

Questions? Call Tanya or Jessica at 1-888-851-7376

ahairaffair.ca

SAVE THE DATE

for your favourite lunch at Budweiser Gardens in London.

MONDAY JUNE 8

11:00 AM – 1:00 PM

STAY TUNED FOR TICKETS!

GREY BRUCE VOLUNTEERS

The South Grey Bruce Hanover and Area Parkinson's group is a special and unique group of individuals. They themselves have decided what their support group will look like. Every second Tuesday of the month, they come to the Saugeen Municipal Airport for a potluck gathering with the 'perfect attitude' - to learn more about their disease, to support each other, to share what they know and to socialize. This group includes those with Parkinson's, their carepartners or supporter. A supporter could include a friend, a daughter, a son, a brother, a sister or a neighbour.

Their motto is, "What can we do to help?" and as a result they are there for each other. If a call is received and someone needs comfort, there is always a small group of volunteers like Doug and Emmy McQuaid to assist. If a member is on a list for having a DBS, Gary Cook and David Ross who have had this procedure, and their spouses, Nancy and Kim, reassure and answer questions so that it is not so scary.

How many Parkinson's groups organize their own walk? This group does. When it became clear that the walk would fold because there was no one to take it on, this group stepped up. Every year, they pull together to make the South Grey Bruce Hanover and Area WALK-IT for Parkinson's happen. They have Rick and Laurie Symonds who every year handle the set up and registration. Everyone in the group does something from serving hotdogs to donating prizes or assisting with clean up.

It is not always easy to go out and ask for money, but more and more people in this group are attempting to take on this challenge. They pound the pavement to get sponsors and pledges. And they do it not just because they themselves have Parkinson's. They are determined to raise money for Parkinson Society Southwestern Ontario to provide programs and support for all, to fight the fight and to support research to find a cure. Clare Poechman summed it up for everyone in this group when he said, "If not a cure for me, then a cure for my children's generation." How selfless is that? Then there is Jerrold Beech who has become an author. He writes humorous short stories that give us our daily chuckle and donates a portion of his earnings to the walk. This group's determination results in raising over $40,000 each year.

Sometimes when you have a degenerative, incurable disease like Parkinson's, you may tend to go into survival mode and your attention is all about you. What makes this group so special? It is not just all about them as individuals. They really care and support each other so they are not an island unto themselves. This small group from small town/rural communities are in the mode of giving more than they receive.

There are the spin-offs from within this special group. Jane Radke's husband Stu has Parkinson's. She decided to initiate a luncheon for carepartners every fourth Wednesday of the month. Somewhere you can go, relax, socialize and talk over concerns and receive that, 'I get what you are saying' feeling. One member of this group says that it is comforting and calming to be part of this group because they understand.

Linda Byers has Parkinson's. She decided she wanted to start a women's luncheon for women with Parkinson's. Somewhere they could go and talk over what is happening with them in a small and confidential setting. So, the first Tuesday of the month, these ladies have lunch together.

The South Grey Bruce Hanover and Area support group hails from a large area, from Port Elgin, Southampton, Dornock, Durham, Hanover, Walkerton, Paisley, Cargill, Mildmay, Mount Forest to Whitechurch, and Wroxeter and areas in between. Yes, the South Grey Bruce Hanover and Area Parkinson's support group is indeed an awesome and unique group because they are a community family.

Pat Troop, Lucy Mavrikkou, Cheryl Losch, Teresa Armstrong (MPP, London Fanshawe), Meg Walden, Mike Hughes and Wayne Walden

Chris Hudson and Pamela Helmes-Hayes

ONTARIO VOLUNTEER SERVICE AWARD RECIPIENTS

Brenda Anderson
Gary Dallner
Danny DeVincenzo
Sarah Hawcutt
Pamela Helmes-Hayes
Chris Hudson
Mike Hughes
Tracey Jones
Cheryl Losch
Bevan Loughheed
Kate Mason
Lucy Mavrikkou
Michelle Napper
Clare Poechman
Jackie Poechman
Bruce Raynard
Nina Raynard
Chris Schaefer
Laurie Symonds
Rick Symonds
Jamie Tolton
Pat Troop
Meg Walden
Wayne Walden

Brenda Anderson

CHECK OUT OUR MONTHLY PARKINSON'S WEBINARS!

Parkinson's webinars are online workshops with expert speakers providing information on important Parkinson's-related topics.

BENEFITS TO WEBINARS:

Convenience
Speakers and participants do not travel to participate.

Informative
A question and answer period follows the presentation.

Cost-Effective
There is no expense of booking meeting space.

Easy
No type of special equipment is needed.

How to participate:
1. Go to parkinsonsociety.ca/events and select a webinar. 2. Click Register. 3. A confirmation email will be sent to you with simple instructions. 4. After the webinar you will receive a recording to review at your leisure.

See page 30 for dates of upcoming webinars.

Thank you Abbvie for supporting our monthly webinars

ATTENTION:
MEDICAL PROFESSIONALS

The Parkinson Education Program (PEP) for Community Caregivers is an online educational series offered to better equip healthcare professionals in providing excellent care to individuals living with Parkinson's disease.

Get your PEP Certificate today!

It's free and makes a difference in the Parkinson's community

www.peponline.ca

ROCK STEADY BOXING

Ann Moore and Larry Skinner

After just two months of dedicated exercise effort at Empire Muscle's Rock Steady Boxing, Ann Moore, 81, walked 40 feet without assistance, despite years of dependency on a walker. According to the program's volunteer coach and director Will Kohler, "We would call this a Christmastime miracle, but it really is due to Ann's own hard work and the personalized attention and encouragement she has been getting. She is a national treasure, and we cherish her."

In fact, Ann's tremendous effort was apparent as she muscled through her early achievement, closely flanked on either side by Kohler and fellow program participant Larry Skinner, who excitedly encouraged her and assured her security. Directly afterward, Ann glowingly said, "I always leave here walking and moving around better than when I come in. It's amazing." Said Skinner, also 81, "She's a trooper, and the program has been amazing for me too."

Empire Muscle's Rock Steady Boxing is brand new, established in September 2019 as a service of Empire Muscle. Empire Muscle is otherwise known as a no-nonsense powerlifting, boxing and conditioning gym on Windsor's west end, at 925 Crawford Avenue.

Well known in the Parkinson's community, Rock Steady Boxing is a (non-contact) boxing-themed exercise program, specifically for people with Parkinson's. The program is proven to significantly mitigate and delay the advancement of Parkinson's symptoms. Rock Steady Boxing has almost 1,000 affiliates around the world, and now two in Windsor.

Empire Muscle's Rock Steady Boxing is offered Tuesdays, Wednesdays and Thursdays at 5:30 p.m. Anyone with any level of Parkinson's symptoms is welcome in the program. There is no evaluation fee. There is a monthly fee that is competitive, sometimes flexible, to encourage participation.

Telephone or text: 519-819-0528. Email: empiremuscle@rsbaffiliate.com. Website: http://empiremuscle.rsbaffiliate.com.

EXERCISE GROUP SCHEDULE

Brantford			
Rock Steady Boxing	2X per week	Bell City Boxing Club 3-23 Tamara Place	$40/month
Cambridge			
Neurological Wellness Exercise Programs	3X per week	Chaplin Family YMCA 250 Hespeler Rd.	YMCA Membership *(Free assessment)*
Rock Steady Boxing	2X per week	Chaplin Family YMCA 250 Hespeler Rd.	YMCA Membership *(Free assessment)*
Chatham – Kent			
SMART Exercise Program	Tuesdays & Thursdays 10:00 am - 11:00 am	Grace Christian Reformed Church 255 Tweedsmuir Ave. W.	Free
Hanover			
SMART Exercise Program	Tuesday & Fridays 10:45 am - 11:45 am	Grace United Church 310 12th St.	Free

These exercise programs are made available through our community partners.

Kitchener

Rock Steady Boxing	3X per week	AR Kaufman YMCA 333 Carwood Ave.	YMCA Membership *(Free assessment)*
SMART Exercise Program	Tuesdays & Thursdays 1:30 pm - 2:30 pm	AR Kaufman YMCA 333 Carwood Ave.	Free (Program offered through Community Support Connections)
Neurological Wellness Exercise Program	3X per week	AR Kaufman YMCA 333 Carwood Ave.	YMCA Membership *(Free assessment)*

Leamington

SMART Exercise Program	Tuesdays 10:30 am - 11:30 am	Leamington and District Half Century Club 160 Talbot St. E.	Free

Listowel

SMART Exercise Program	Tuesdays & Fridays 2:15 pm - 3:15 pm	VON Office 975 Wallace Ave. N.	Free

London

Exercise Group	Wednesdays & Thursdays (Alternate Weeks) 12:00 noon - 1:00 pm	Parkwood Day Hospital 550 Wellington Rd.	$5 / Class
SMART Exercise Program	Mondays & Thursdays 2:00 pm - 3:00 pm	Carling Heights Optimist Community Centre, 656 Elizabeth St.	Free
Rock Steady Boxing	3X per week	Southside Group 75 Blackfriars St.	$100 / Month

Owen Sound

SMART Exercise Program	Tuesdays -1:00 pm - 2:00 pm Thursdays - 1:30 pm - 2:30 pm	First United Church 435 21st St. W.	Free
Rock Steady Boxing	2X per week	YMCA of Owen Sound Grey Bruce 700 10th St. E.	YMCA Membership

Sarnia - Lambton

Exercise Group	Thursdays 11:00 am - 11:45 am	Strangway Centre 260 East St.	Strangway Member - $2.25/class Non-Member - $5/class
Rock Steady Boxing	2X per week	Ironworks Fitness	$70 / Month

Stratford

Gentle Yoga Group	Mondays 10:00 am - 11:00 am	Army, Navy and Air Force Veterans Centre, 151 Lorne Ave. E.	$7 / Class

Strathroy

SMART Exercise Program	Mondays - 11:30 am - 12:30 pm Wednesdays - 1:00 pm - 2:00 pm	Westmount Christian Reformed Church, 405 Drury Lane	Free

St. Thomas

SMART Exercise Program	Mondays & Thursdays 10:00 am - 11:00 am	Elgin Mall 417 Wellington St.	Free

Windsor

SMART Exercise Program	Wednesdays 1:30 pm - 2:30 pm	Windsor YMCA 3400 Grand Marais Rd. E.	Free
Rock Steady Boxing	3X per week	Border City Boxing Club 1072 Drouillard Rd.	$100 / Month
Rock Steady Boxing	3X per week	Empire Muscle 925 Crawford Ave.	$80 / Month *(Free assessment)*

Information is current at time of print. Please call 1-888-851-7376 before attending your first exercise program. Please check our website at www.parkinsonsociety.ca for the most up-to-date information.

REGIONAL SUPPORT GROUPS

Brantford

Support Group	Every 2nd Wednesday of the month (excluding July & Aug) 2:00 pm – 4:00 pm	John Noble Home 97 Mount Pleasant Rd.

Cambridge

Support Group	Every 2nd Wednesday of the month (excluding Jan & Feb) 1:00 pm – 2:30 pm	Chaplin Family YMCA 250 Hespeler Rd.

Chatham – Kent

Support Group	Every 2nd Tuesday of the month (Jan, Mar, May, Sept, Nov) 6:30 pm – 8:00 pm	Active Lifestyle Centre 20 Merritt Ave.
Luncheon Group	Every 2nd Thursday of the month (Feb, Apr, Jun, Oct, Dec) 11:30 am – 1:00 pm	Active Lifestyle Centre 20 Merritt Ave.

Dunneville

Support Group	Every 4th Tuesday of the month 6:30 pm – 8:00 pm	Grandview Lodge 657 Lock St. W.

Fergus

Support Group	Every 3rd Tuesday 2:00 pm – 4:00 pm	St. Joseph's Catholic Church 760 St. David St. N.

Goderich – Huron

Support Group	Every 1st Tuesday of the month (excluding Jan-Mar) 2:30 pm – 4:00 pm	MacKay Senior Centre 10 Nelson St. E.

Grand Bend

Support Group	Last Monday of the month (excluding Jun, July, Aug & Dec) 2:00 pm – 3:30 pm	Grand Bend Area Community Health Centre 69 Main St. E.

Hanover

Support Group	Every 2nd Tuesday of the month (Apr-Nov) 5:30 pm – 7:30 pm	Saugeen Municipal Airport 34 Saugeen Airport Rd.
CarePartner Group	Every 4th Wednesday of the month 1:00 pm – 3:00 pm	Cravings Family Restaurant 208 7th Ave.
Luncheon Group	Every 1st Tuesday of the month 12:00 noon – 1:30 pm	Cravings Family Restaurant 208 7th Ave.

Kincardine

Support Group	Every 2nd Tuesday of the month (excluding Dec-Feb) 12:00 noon – 1:30 pm	Location varies. Call Mark Womack at 1-888-851-7376.

Kitchener

Support Group	Every 3rd Thursday of the month (excluding July, Aug & Dec) 6:30 pm – 8:00 pm	Briarfield Gardens Retirement Residence 1250 Weber St. E.

Leamington

Support Group	Every 1st Tuesday of the month (excluding July & Aug) 11:30 am – 12:30 pm	Leamington and District Half Century Club 160 Talbot St. E.

London

Support Group	Every 3rd Saturday of the month (excluding July & Aug) 2:00 pm – 4:00 pm	Trinity Lutheran Church 746 Colborne St.
CarePartner Group	Last Tuesday of every month (excluding Jul & Aug) 1:30 pm – 3:00 pm	Berkshire Club 500 Berkshire Dr.

Meaford

Support Group	Every 3rd Tuesday of the month 2:00 pm – 4:00 pm	Meaford United Church 7 Boucher St. E.

Orangeville

Support Group	Every 2nd Wednesday of the month (excluding July & Aug) 7:00 pm – 8:30 pm	Alzheimer Society 25 Centennial Rd.

Owen Sound

Support Group	Every 2nd Tuesday of the month 2:15 pm – 3:30 pm	The New Life Centre, Christian Reformed Church 199 4th Ave. W.

Sarnia - Lambton

Support Group	4th Wednesday (excluding Jun, Jul & Aug) 2:00 pm – 4:00 pm	Clearwater Arena Community Room 1400 Wellington St.

Simcoe

Support Group	Every 3rd Thursday of the month (excluding July & Aug) 1:00 pm – 3:00 pm	Welling's of Waterford 111 Bruce St., Waterford

Stratford

Support Group	Every 2nd Tuesday of the month (excluding July & Aug) 1:30 pm – 3:30 pm	Army, Navy and Air Force Veterans Centre 151 Lorne Ave. E.

Strathroy

Support Group	Every 3rd Tuesday of the month (excluding July & Aug) 1:30 pm – 3:00 pm	Westmount Christian Reformed Church 405 Drury Lane

St. Thomas

Support Group	Every 2nd Tuesday of the month (excluding July & Aug) 2:00 pm – 4:00 pm	Knights of Columbus Hall 265 Wellington St.

Tillsonburg

Support Group	Every 3rd Thursday of the month (excluding July & Aug) 1:00 pm – 2:30 pm	Tillsonburg Retirement Residence 183 Rolph St.

Waterloo

Support Group	Every 4th Wednesday of the month (excluding July, Aug & Dec) 10:30 am – 12:00 noon	Westhill Retirement Residence 25 Westhill Dr.

West Lorne

Support Group	Every 4th Thursday of the month (excluding Aug) 10:30 am – 12:00 noon	The Hub 146 Munroe St.

Windsor

Support Group	Every 4th Tuesday of the month (excluding Dec) 7:00 pm – 8:30 pm	Windsor Community Living Support Services 7025 Enterprise Way

Woodstock

Support Group	Every 4th Monday of the month (excluding July & Aug) 2:00 pm – 4:00 pm	UNIFOR 126 Beale St.

Please call 1-888-851-7376 before attending your first support group.
Please check our website at www.parkinsonsociety.ca for the most up-to-date information.

2020 REGIONAL PARKINSON'S EVENT CALENDAR

JANUARY

22 **WEBINAR: Advanced Therapies for Parkinson's**
Dr. Devin Hall
12:00 noon – 1:00 pm

FEBRUARY

19 **WEBINAR: Medications and Parkinson's**
Greta Mah, Board Certified Geriatric Pharmacist
12:00 noon – 1:00 pm

MARCH

18 **WEBINAR: Sleep and Fatigue in Parkinson's**
Dr. John Paulseth
12:00 noon – 1:00 pm

APRIL

7 **Living Well Conference: Your Physician, Your Pharmacist and You (Brantford)**
Best Western Brantford Hotel and Conference Centre
10:00 am – 2:00 pm

14 **Living Well Conference: Your Physician, Your Pharmacist and You (Zurich)**
Hessenland Inn
72981 Bluewater Highway
9:00 am – 2:00 pm

15 **Annual General Meeting**
Parkinson Society Southwestern Ontario
117-4500 Blakie Rd., London
5:00 pm

21 **Living Well Conference: Your Physician, Your Pharmacist and You (Kincardine)**
Kincardine Hall, Davidson Centre
791 Durham St
9:00 am – 2:00 pm

22 **Living Well Conference: Your Physician, Your Pharmacist and You (Chatham)**
John D. Bradley Convention Centre
565 Richmond St
9:00 am – 2:00 pm

22 **WEBINAR: Feeling Faint – Sudden Drop in Blood Pressure in Parkinson's**
Dr. Joyce Lee and Greta Mah
12:00 noon – 1:00 pm

26 **Hair Affair for Parkinson's**
Cambridge, Kitchener, London and Waterloo
(See page 23 for details)

MAY

12 **Financially Preparing for Parkinson's (Owen Sound)**
Details to be confirmed

20 **Mindfulness & Movement Workshop (Windsor)**
Ojibway Nature Centre
5200 Matchette Rd

MAY (CONTINUED)

22 **WEBINAR: Psychological Changes in Parkinson's**
Susan MacDonald
12:00 noon – 1:00 pm

27 **Neurological Perspectives on Healthcare (Sarnia)**
St Clair Corporate Centre
265 Front St N
5:30 pm – 7:30 pm

27 **Neurological Information Night (Cambridge)**
Dr. Dwight Stewart
Langs
1145 Concession Rd
6:00 pm – 8:00 pm

27 **11th Annual Parkinson Golf Classic - Presented by Rembrandt Homes (London)**
West Haven Golf & Country Club

JUNE

8 **8th Annual SIGNATURES – A Taste Test of London's Best**
Budweiser Gardens, London
(See page 23 for details)

16 **3rd Annual SIGNATURES – A Taste Test of Waterloo Region's Best**
Waterloo Memorial Recreation Complex
101 Father David Bauer Dr. Waterloo
(See page 31 for details)

For more information, to keep updated and to become involved in our special events, go to www.parkinsonsociety.ca, call 1-888-851-7376 or email info@parkinsonsociety.ca.

SEPTEMBER

12 **WALK-IT for Parkinson's**
Brantford-Brant County – Mohawk Park
Goderich – Rotary Cove Pavilion
London and District – Springbank Gardens
South Grey Bruce and Hanover – Hanover Town Park
Stratford and Area – Upper Queen's Park
Waterloo Region – Kiwanis Park
Wellington-Dufferin – Centre Wellington Sportsplex

13 **WALK-IT for Parkinson's**
Chatham-Kent – Kingston Park
Owen Sound – Harry Lumley Bayshore Community Centre
Port Elgin, Kincardine and Area – North Shore Park, Saugeen Shores
Strathroy and Area – Strathroy Seniors Centre
Tillsonburg-Norfolk County – Memorial Park
Windsor-Essex – Malden Park (Visitor Centre Entrance; 4200 Malden Road)
Woodstock-Ingersoll – South Gate Centre

20 **WALK-IT for Parkinson's**
Grand Bend – Grand Bend Public School
Sarnia-Lambton – Canatara Park

Visit **www.walk-it.ca** for more details.

In Memoriam

We offer our sympathy to the families whose loved ones have passed away between July 1, 2019 and December 31, 2019

Olive Aitken
Maria Andrade
James Angood
James Archibald
Robert Barker
Dorothy Barlow
Patricia Becker
Marcella Berg
Kirk Bice
Marvin Bildfell
Francis Boone
Ronald Booth
Bernice Bradstock
Don Braithwaite
David Braun
Kathleen Brenner
Dave Brown
Frank Bruno
Jim Burgess
Magda Chase
Suzanne Chovanec
Dennis Clark
Errol Cochrane
Constance Couse
Robin Crapper
Gary Cromarty
Betty Czoll
Natalina Dal Farra
Lucille Dallaire
Assunta Dall'Armi
George Debono
Donald Denby
Wilson Dennis
Donna DePelsmaeker
Peter Doiron
Christiaan Dokter
Stanley Down
Sue Dunseith
Cecil Dykstra
Shirley Eaton
Chris Ecclestone
Marion Elliott
Barbara Farkas
Norm Farmer
Vincent Fava
Donald Fenn
James Fenn
Gilbert Finley
Gordon Fitzgerald
Drika Foster
Eric Fowler
Nancy Fox
Lawrence Fric
Mark Gee
Gordon Gibson
Dr. G.D. Glennie
Bob Goudeseune
Clarence Green
Vito Grillo
Elizabeth Grove
Dennis Halk
Marie Harris
Dona Hayward
Val Heisler
Karen Hillis
Merla Hopper
Leslie Horvath
Margaret Hotz
Elizabeth Hunter
Judith Janisse
Mary Jarema
Mervin Johnson
Noreen Kelly
Barbara Kennedy
Joy Kerslake
Richard Kunder
Theresa Lacroix
Donald Leitch
Priscilla Lemire
Marie Lenart
Gizela Lesic
Gary Letcher
Jean Linton
John Lochhead
Maria de Lourdes Lopes
David Lovell
Irene Matisz
Bruce McGlynn
John McGuire
Frank McMurchy
Peter Mellor
Pearl Merla
Roger Moriarity
Dennis Murphy
Jacob Nostadt
Jerry Novak
June Oost
Adele Otten
Pashalis Papaioannou
Marilyn Park
Clara Parsons
Corbin Pearson
Marian Penhale
Robert Perry
Nancy Peseski
John Piggott
Reginald Pitre
Pierrette Poulin
Anthony Pritchard
Marjorie Ptolemy
Gerald Rand
Carol Rankin
Carl Rasmussen
Muriel Rawlings
Barry Raymond
Robert Repa
Beulah Reynolds
Earl Ritchie
Tony Rizzo
Beatrice Santamaria
Doris Sawer
Gladys Schnarr
Herbert Shannon
John Shannon
James Sharrard
Donna Shaw
Albert Simon
Jennie Sinden
Alyce Small
John Speirs
Herb Stammler
Delford Stemmler
Maurice Stephenson
Edward Stevens
Joy Sutherland
Rick Sylver
David Thompson
Rosemary Thoms
Robert Tonato
Kenneth Totzke
Stuart Trotter
Frank Tubman
Clemens Van Beest
Rochus Van Meer
Judy Vanderheide
Silvana Viani
Kees Vreugdenhil
Douglas Walker
Wilhelmiena Wardell
Edgar Warnhoff
Mathilde Watkins
Clayton Weber
Dr. Michael Weber
Betsy Welsh
George Werezak
Frederick Westlake
Ferne Wickenheiser
Jim Wilson
Nigel Wood
George Woodall
Jean Woodhouse
Edward Yurek
Gustav Zytner

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.

PARKWOOD EDUCATION PROGRAM
(LONDON)

This seven-week program increases awareness and provides coping strategies for individuals with Parkinson's and their carepartners.

What to expect during each visit:

- A one-hour education session provided by skilled healthcare professionals to address the following areas:
    - Signs and symptoms of Parkinson's
    - Disease progression and management of physical symptoms
    - Medication management
    - Mobility issues
    - Speech and swallowing issues and nutrition
    - Adaptive equipment for self-care
    - Energy conservation and relaxation
    - Health benefits of leisure
    - Overcoming barriers to leisure
    - Social and emotional aspects of the disease and adjustment process
- A 1½ hour exercise class, led by a physiotherapist
- A support group for carepartners, led by a social worker
- Refreshments

Call 1-888-851-7376 for more information.

SAVE THE DATE
for your favourite lunch at Waterloo Memorial Rec Complex

TUESDAY, JUNE 16

11:00 AM – 1:00 PM

STAY TUNED FOR TICKETS!

WALK-IT PARKINSON'S

Who will you WALK-IT for?

September 12, 13 & 20
at a park near you!

Stay tuned for more information.
www.walk-it.ca

Volunteers Needed!

Call 1-888-851-7376 or email vickie.thomas@parkinsonsociety.ca
to find out how you can help!