



THE PARKINSON'S UPDATE

SUMMER/FALL 2020 • ISSUE 72



We're here for **YOU!**

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MISSION STATEMENT

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

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Front Cover Photos:

(from left to right): Carolyn Young, David Brown, Sue Pullam, Ron Young, Kelly Campbell-Brown and Gary Pullam. Watch a series of Parkinson's videos with Carolyn, David, Sue, Ron, Kelly and Gary by going to <https://parkinsonsociety.ca/here-for-you/>

FROM THE CEO's DESK



Shelley Rivard

Here we are halfway through 2020 and what a year it has been so far! I am sure most would agree that it has been a bit of a bumpy ride adapting to life through COVID-19. And now, as we start to see our communities begin to open up, what does our "New Normal" look like? Is it safe?

Parkinson Society Southwestern Ontario (PSSO) is asking the same questions. For us, the safety and wellbeing of our clients are first and foremost in our minds.

As PSSO anticipates the gradual re-opening of our office to the public on Tuesday, August 4, we are having to implement safety measures for clients, volunteers and staff. If you are planning to visit, we would love to see you. Please connect with our office first to learn what you need to know prior to visiting.

In February, PSSO received 13 applications for our Graduate Student Scholarship Awards. Just recently, we awarded three Graduate Student recipients a total of \$50,000. (see page 6-7)

For me, summer always means preparations are under way for our largest fundraiser, our walks. This will be the first event we will be able to hold this year, although it will look different. Last year, because of each of you, an amazing \$466,000 was raised. This year, I am excited for our new normal and **"WALK THE BLOCK for Parkinson's"**. At a time where social distancing is imperative and we are not able to gather as one large group, we can still participate as an individual or family team, walking around our own individual blocks as we raise much needed funds, necessary to support those living with Parkinson's in Southwestern Ontario. This year more than ever, we hope we can count on you to **WALK THE BLOCK for Parkinson's!**

As we continue into the fall, with concerns of a second wave of COVID-19, PSSO will continue to be vigilant in keeping everyone safe. All programs and in-person group meetings will continue to be done virtually. I know that everyone is looking forward to the day when we can once again have in-person group meetings. I know that day will come; I just don't know when.

I know many of you enjoy the Fall Regional Conference we have each year. We have a fantastic group of speakers for 2020: Dr. Quincy Almeida, Dr. Patricia Rosebush, Dr. Mandar Jog and Erind Alushaj, one of our funded Graduate Student recipients. As well, this conference will be done virtually (see flyer). There is no cost associated with attending the conference this year, but if you are able to make a donation, we would truly appreciate it.

This year has been different in so many ways. As PSSO continues to adapt to our ever-changing new reality, we want you to know that **HOPE is close to Home.**



Shelley Rivard
CEO

WE'RE HERE FOR YOU!

Parkinson Society Southwestern Ontario has been working hard to find new ways to keep the Parkinson's community connected to the support and resources you need to help live life to the fullest.

Parkinson's Virtual Support Groups

COVID-19 has changed our world as we know it through social distancing and/or self-isolation. It is important now more than ever to find a way to be a support for one another. To find a virtual support group in your area, go to <https://parkinsonsociety.ca/virtual-support-groups/>. Join Lisa Nixon, Information & Referral Specialist, in a virtual Coffee Klatch every Tuesday at 10:00 am this summer.

Parkinson's Exercise Programs

Exercise – Keeping it Virtual. With COVID-19 restrictions easing or being lifted, your health and safety continues to be our top priority. We ask that you hold off in attending in-person exercise programs for now. We have compiled this list of virtual exercise programs to help you keep active. For more information, go to <https://parkinsonsociety.ca/parkinsons-exercise-programs/>

WALK THE BLOCK for Parkinson's

Parkinson's Disease knows no boundaries and can affect anyone. Maybe you're walking for your mother, father, brother, sister, son, daughter, grandmother, grandfather, aunt, uncle, cousin, friend or even yourself.

So, let's continue in that spirit and be unstoppable this September as we WALK THE BLOCK for Parkinson's (see pages 21-22).

The Parkinson's E-News Update

We offer weekly up-to-date information on Parkinson's programs and resources by email. If you are interested in receiving the weekly Parkinson's E-News Updates, email info@parkinsonsociety.ca.

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.

To find out about upcoming webinars, go to parkinsonsociety.ca or email info@parkinsonsociety.ca.

2020 REGIONAL PARKINSON'S VIRTUAL CONFERENCE

October 17, 2020
9:00 am – 1:15 pm

SPEAKERS:

Dr. Quincy Almeida

Professor, Department of Kinesiology and Physical Education; Director, Movement Disorders and Rehabilitation Centre

Dr. Patricia Rosebush

Professor, Department of Psychiatry & Behavioural Neurosciences

Erind Alushaj

Research Student, Western University

Dr. Mandar Jog

Professor, Department of Clinical Neurological Sciences, Neuroscience, Physiology and Pharmacology, Neurology, Schulich School of Medicine & Dentistry, Western University

Cost: Donation if you are able

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



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

Regional Office:

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

✉ info@parkinsonsociety.ca

🌐 www.parkinsonsociety.ca

📌 ParkinsonSocietySWO

📷 [parkinsonswo](https://www.instagram.com/parkinsonswo)

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

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

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

It has been eight years since we first shared the story of Clare Poechman (*The Parkinson's Update*, Issue 55) and he doesn't seem to be showing many signs of slowing down. Clare was diagnosed with Parkinson's 13 years ago at the age of 59.

When he was first diagnosed, he kept quite busy with golf, his home renovation business, coaching a ball team, helping to start a new Parkinson's support group in the area and getting involved in fundraising to help those living with the challenges of Parkinson's. He was also dealing with anxiety and depression.

Now, Clare no longer golfs; he simply lost interest. He is still involved with home renovations for his family members; he just doesn't go on ladders. He is amazed and thankful he is doing so well and says he can do almost anything, if he just takes his time.

The support group is going strong and Clare attends because the interactions with others in the group are still very helpful.

Clare has been participating in the South Grey Bruce and Hanover Walk for Parkinson's since 2009. He "pounds the pavement" and secures personal as well as corporate donations in the community. To date, he has raised more than \$170,000!

As for Clare's anxiety and depression, he feels it is under control with a combination of regular exercise, natural products and timely medication. His regular exercise routine consists of chair yoga once a week, the VON SMART exercise program twice a week and daily walks. Since COVID-19, Clare exercises online and continues with his walks.

When asked what advice he would give someone newly diagnosed, Clare says, "Accept it. Don't fight it. No matter how bad things get, there are always people worse off than you. If you can, join a local support group. It is a major help to hear others' issues and how they solved them. It is good to connect with people dealing with some of the same challenges."

Clare is a great example of "I have Parkinson's, but it doesn't have me."



Jackie and Clare Poechman

Canadian Open Parkinson Network

Canadian Open Parkinson Network (C-OPN) is creating an innovative national platform to bridge people, data and resources to accelerate Parkinson's disease discoveries. To make this initiative a reality, the network needs people with Parkinson's disease and Parkinson Plus Syndromes across Canada to sign up (<https://app.copn.researchcalgary.ca/selfRegistration/en>) and participate. As a participant in the network, you will have the opportunity to:

- 1) Participate in the creation of a national database collecting information on people with Parkinson's disease or Parkinson Plus Syndrome for researchers across Canada
- 2) Participate in the creation of a national biobank for Parkinson's disease or Parkinson Plus Syndrome for researchers
- 3) Learn more about other research opportunities happening across Canada

For more information, go to <https://copn-rpco.ca/participants/>



CARING FOR YOURSELF

Being a caregiver can impact your health and wellness, as well as your relationships with family and friends. It's important to take a break and avoid burnout. Taking care of yourself is as important as caring for someone else.

The most important coping strategies are:

- Eat right – Balanced nutrition is essential to keeping up your own health and energy.
- Exercise – Moving your body helps alleviate depression and increases your endorphins (coping hormones).
- Sleep – It may be hard to get seven-eight hours a night, but rest is key to resiliency and proper functioning.
- Connect – Finding someone to talk to, be it a family member, friend or peer support group, is crucial to handling your own emotions and the stress of caregiving.

Emotions and What to Expect

While most caregivers have a positive outlook on their experience and a sense of fulfillment, two-thirds admit they had no choice but to assume the work of caregiving.

Regardless of why or how you became a caregiver, there are many emotions that arise from taking on the responsibilities involved with caregiving. Some of these will come up right away, while others may take time to surface or be difficult to express.

You may feel tired, frustrated, anxious, overwhelmed, depressed, lonely, resentful, irritable, afraid, angry, and a variety of other emotions (see <https://www.caregiver.org/emotional-side-caregiving>). These are all normal and may be part of your caregiving experience.

In order to manage your own emotions, it is important to take care of your own needs. Ask for help and support from:

- Family members or friends
- Spiritual or religious groups
- Community or peer support groups
- Specific disability or illness organizations
- Therapist, counsellor, social worker
- Respite services

Finding Respite

A temporary rest is called respite or respite care. The care provided by a community agency can also be called respite services. This support can be provided inside or outside your home and ensures the person you support is being cared for while you care for yourself.

Find respite in your community by calling the Ontario Caregiver Helpline. You can also visit: www.respiteservices.com.

For more information on caregiving and resources, go to <https://ontariocaregiver.ca/resources/caring-for-a-senior/#caring-for-yourself>

Mental Health

While many caregivers find their role rewarding, previous research from Health Quality Ontario has shown that one in four caregivers is experiencing distress, anger or depression and according to the Canadian Institute of Health Information, 45% of caregivers of those with dementia are experiencing distress.

An opinion poll from Ontario Caregiver Organization (OCO) indicates that 46% of caregivers who support someone with a mental health challenge are not handling the situation well. 57% say they are not coping well emotionally and 47% say they are not coping well physically. A strong majority agree they often feel anxious or worried (87%), overwhelmed (85%), frustrated, helpless and trapped (82%) and are getting disturbed sleep (80%).

To read the Caregiver Mental Health Wishlist go to <https://ontariocaregiver.ca/publications/mental-health-wishlist/>

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



Graduate Student Research Program

The Graduate Student Research Program is part of a strategic initiative to encourage young scientists to enter the field of Parkinson's research, and to invest in research and training that offer promise for future work. We were excited to award funds totaling \$50,000 to three graduate students: Erind Alushaj, Kishoree Sangarapillai and Natalie Porte-Trachsel.



RESEARCHER: Erind Alushaj, Western University

GRANT: \$20,000

PROJECT TITLE:

Uncovering Preclinical Biomarkers of Parkinson's Disease in Patients with REM Sleep Behaviour Disorder

My research focuses on using magnetic resonance imaging (MRI) to uncover changes in the brain related to Parkinson's disease. Specifically, we are interested in changes that are present before the appearance of Parkinsonian symptoms. These changes are called preclinical biomarkers. Their discovery will help uncover the cause of Parkinson's disease, provide targets for therapy and forecast the development of Parkinson's disease even before symptoms arise. Preclinical biomarkers would also help clinical trials looking to develop novel medication.

Patients with rapid eye movement sleep behaviour disorder (RBD) provide a truly unique opportunity to study preclinical biomarkers of Parkinson's disease. The majority of patients with RBD will develop Parkinson's disease within 10 years of their diagnosis. Since years can pass until the first Parkinsonian symptoms appear, this creates a large enough window to study these preclinical changes in the brain. These observations have led researchers to reclassify RBD from a simple sleep disorder to an early manifestation of Parkinson's disease.

Patients with RBD will be scanned in a 7-Tesla MRI at the Robarts Research Institute. MRI is a safe and non-invasive imaging technique that allows researchers to look at the integrity of brain structures. Furthermore, the 7-Tesla MRI can take incredibly detailed images of the brain and is just one of two such scanners in Canada.

We will assess the brain structures that are primarily impacted by Parkinson's disease to see if we can find similar changes in patients with RBD. Looking for these 'Parkinsonian' changes in patients with RBD would eventually lead to the discovery of preclinical biomarkers. This would ultimately have major implications on how we diagnose, treat and manage Parkinson's disease.



RESEARCHER: Kishoree Sangarapillai, Wilfrid Laurier University

GRANT: \$15,000

PROJECT TITLE:

Evaluating the Effects of Cognitive Rehabilitation vs. Sensory Training on Gait Impairments in Parkinson's Disease: A Randomized Controlled Trial

Walking difficulties are one of the most challenging and disabling symptoms for those with Parkinson's disease as it may lead to injuries, increased stays in hospital/long-term care facilities and overall poor quality of life. Currently, there is some debate over the causes of these walking challenges. Some research suggests that challenges with walking are due to problems with cognition. In

Please note: Ask the Expert is not available in this issue of The Parkinson's Update with the effects of COVID-19 on the workloads of healthcare professionals. Look for this section to be back in issue 73 of The Parkinson's Update. In the meantime, please direct questions for the Ask the Expert section to info@parkinsonsociety.ca

other words, walking for those with Parkinson's may require a lot of attention and conscious effort directed towards surroundings. This may make it harder for the brain to control walking.

On the other hand, other research points to sensory impairments that make walking more difficult. In other words, individuals may have trouble making sense of the sensory information from the surrounding environment making walking more difficult. For example, detecting small slopes in the ground while walking around the house or feeling the sidewalk beneath one's feet may make walking more difficult.

Unfortunately, the common medications for Parkinson's have very little effect on cognition and sensory impairments. So it is not surprising that medications cannot completely improve the challenges with walking. Therefore, the goal of my research is to improve walking by improving cognition and sensory impairment using exercise. I hope to have at least 100 participants in my study and I will randomly place them in one of two exercise groups.

Based on the dementia literature, the first group will aim to improve cognition using a high intensity exercise (PDSAFExTM+aerobic). Whereas the second group will focus on sensory training (PD SAFExTM+sensory limb matching) to enhance the use of sensory feedback while walking. This will be the largest rehabilitation trial conducted in Canada and, through the results of this study, I hope to improve the challenges with walking that those with Parkinson's face on a daily basis.



**RESEARCHER: Natalie Porte-Trachsel,
University of Guelph**

GRANT: \$15,000

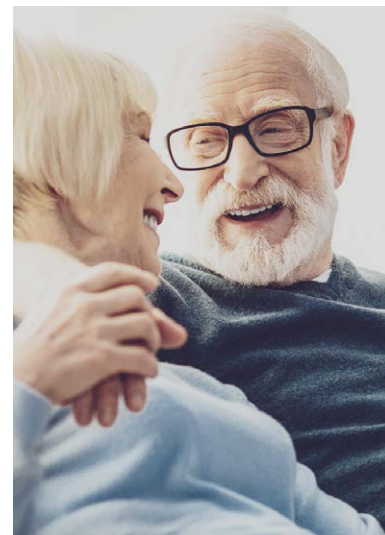
**PROJECT TITLE:
Investigating the Spread of Parkinson's
Disease Pathology from Diseased to
Healthy Cells**

Parkinson's disease (PD) is the second most prevalent neurodegenerative disease worldwide and the most common human movement disorder, affecting over 100,000 Canadians. Characterized by a progressive decline in voluntary movement, motor function eventually dissipates, and patients lose the ability to move. To date, there is no effective treatment capable of halting or reversing disease pathology.

While many anatomical brain regions are affected in PD, dopamine-producing neurons in the midbrain are most susceptible to degeneration. Identification of the specific cell-type and anatomical region that is lost in PD has led many to postulate that an effective treatment to repopulate this brain region is stem cell therapy. Some early successes are driving collaborative efforts towards clinical trials to assess the efficacy of stem cell-based approaches to regenerative therapy.

While the excitement surrounding cell replacement therapy cannot be denied, questions still arise regarding the impact that the host environment may have on grafted cells or tissue. Indeed, analysis of graft tissue from human PD subjects who received grafts of embryonic brain tissue revealed Lewy body pathology (a hallmark of PD) within the donor tissue. This suggests that diseased host tissue is able to transmit pathology to the graft. In support of this, our lab is the first to show that samples derived from PD patients can transmit pathology in a cell-to-cell manner, triggering disease in previously healthy cells.

My research will focus on determining whether PD pathology can move from diseased cells into a healthy brain. If successful, this study will yield a novel model for studying PD.



Louder, Clearer:

a Parkinson's Voice Training Program

Group sessions sponsored by Parkinson Society Southwestern Ontario and led by speech-language pathologists provide an opportunity for people with Parkinson's in Southwestern Ontario to learn and practise skills for louder, clearer speech in a relaxed and social atmosphere.

Louder, Clearer: a Parkinson's Voice Training Program is offered twice a year, generally in the fall and spring in several areas throughout the region, including London, Kitchener, Windsor and Online.

Cost: FREE!

Register early as space is limited.

For more information about the program or to register, please contact info@parkinsonsociety.ca or call 1-888-851-7376 ext. 28.



RESEARCH UPDATE:

Attending to the Psychosocial Support Needs Experienced by Caregivers

Dr. Jeffrey Holmes, Dr. Andrew Johnson and Dr. Liliana Alvarez

It is widely acknowledged that family members, commonly referred to as carepartners or informal caregivers, play a vital role in the care of people with Parkinson's (PD), providing social, physical and psychological support. While they do not receive formal training, it is estimated that caregivers perform upwards of 50 hours of caring per week. Although caring for a relative can be a rewarding experience, providing care over an extended period of time often results in adverse effects for the caregiver. A significant proportion of caregivers report that their health has suffered as a result of providing care, with up to 50% experiencing exhaustion and depression that is linked to their caregiving role.

Although a number of studies have contributed to the knowledge base of caregiver burden in PD, only one published study has examined the caregiver experience within Southwestern Ontario. Results from this study identified that the primary source of caregiver burden for the five participants (all of whom were female) was derived from mental aspects of caregiving, with an emphasis on social isolation and safety concerns of the caregiver. Recommendations were made advocating for more education to be directed towards coping with these mental stressors. While these findings were reported almost a decade ago, recent evidence produced by our research team suggests that caregivers within Southwestern Ontario remain underserved and lack adequate accessibility to information and caregiver supports. For example, as part of a larger CIHR investigation (Holmes, Johnson, & Rudman \$99,440) designed to capture the psychosocial implications of living with PD from the patient's perspective, we noted caregivers expressed the following concerns:

"People ask [Person with PD] how are you doing but they don't turn to me [Caregiver] and say how are you doing. It's more like I'm sorry you're going through this. Yeah, I'm sorry I'm going through this too"

"Even after the six weeks at [Hospital] for the Parkinson's workshops, I called and asked if the social worker that I saw for those six weeks was available, that I would like to talk to her and she said not really but we'll make an exception if the two of you come in. And we spent an hour talking to her and most of the conversation was towards [Person with PD] I didn't feel like I could really talk."

"Because I think, sometimes, caregivers get lost in the loop and they're not acknowledged. The illness is so visual and so a part of the experience is that the caregiver is kind of to the side of it all happening."

Given these findings, Parkinson Society Southwestern Ontario partnered with Western University to support a research study designed to gain an updated understanding of the unique burden and unmet support needs experienced by caregivers of individuals with PD in Southwestern Ontario. This research was carried out in two phases:

Phase I

Phase 1 focused on capturing what caregivers identify as their prominent unmet support needs (needs assessment). To accomplish this, caregivers across Southwestern Ontario were asked to complete an online survey measuring how their life has been impacted by their caregiving responsibilities and/or to participate in a workshop designed to elicit information about the supports that caregivers access, and/or would like to access to help manage their role. Forty-three caregivers completed the online survey, and six workshops that collectively involved 95 caregivers were held across the region: Cambridge, Walkerton, Stratford, Windsor, Woodstock and Waterloo.

Results identified that caregivers report experiencing Mild to Moderate levels of burden, with levels ranging from little or no burden to severe burden. Primary concerns raised by caregivers during the workshops highlighted that i) caregivers remain uncertain how to access formal supports including: Occupational Therapy, Physical Therapy, Speech Language Pathology and Respite Care; and ii) caregivers feel underprepared and experience considerable anxiety when having to navigate difficult discussions with the person receiving care. Emphasis was placed on having to manage discussions related to driving cessation, alternate living arrangements and relinquishing power of care and power of attorney.

Phase II

Phase II focused on identifying the presence of, and access to, resources and services for caregivers of individuals with PD in Southwestern Ontario (environmental scan). Semi-structured interviews were conducted with key personnel from Parkinson Society Southwestern Ontario and Parkinson Canada. Guiding questions probed to identify what programs, services, supports and other resources exist that serve caregivers of individuals with PD. A review of resources available online from each of the societies' websites was also undertaken. While data analysis remains ongoing, several important resources were identified by Parkinson Society Southwestern Ontario and Parkinson Canada. These supports include: Educational pamphlets; Carepartner guidebook; Caregiver Conferences; Caregiver Support Groups; Caregiver self-assessments; Consultations with information and referral specialists; and several caregiver resources that are available online.

ACKNOWLEDGMENTS: The authors wish to kindly acknowledge the efforts of Western student researchers Abigail Reid, Klaire Gain and Lisa Moszczynski for their help with undertaking this project. We would also like to thank all the participants who contributed their time and thoughtful experiences and Parkinson Society Southwestern Ontario and the University of Western Ontario for providing financial support.

Online Caregiver Resources

<https://www.caregiverexchange.ca/> If you're caring for a family member or friend who is facing the challenges of age, disability, illness or injury, Caregiver Exchange can connect you with a wide range of information, services and supports.

<https://www.dementiacarers.ca/> The Reitman Centre, Sinai Health System and Alzheimer Societies across Ontario provide in-person and online programs for people caring for family members or friends living with dementia.

<https://caregivingmatters.ca/> Caregiving Matters is an internet-based registered charity offering education and support to family caregivers.

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx The Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, healthcare providers, researchers and educators.

<https://youngcaregivers.ca/> The Powerhouse Project offers online resources and articles for Ontario's young carers – youth and young adults, who are in a caregiving role for a family member needing assistance with their daily-lived experience.

<http://www.ontariocaregivercoalition.ca/> The Ontario Caregiver Coalition is dedicated to recognizing the importance of unpaid caregivers in Ontario by raising awareness of the value they add to the healthcare system, and by advocating for improved, fair access to needed supports. OCC strives to be the voice of caregivers in the province.

<https://www.carerscanada.ca/> Established in 2000, Carers Canada is a virtual alliance of diverse partner organizations that work collectively, and autonomously, to identify and respond to the needs of caregivers in Canada.

<https://ontariocaregiver.ca/> The Ontario Caregiver Organization is a one-stop resource for caregivers seeking support. Explore the resources available to you through our 24/7 Caregiver Helpline and Live Chat. Caregiver Helpline. Caregiver Resources. 24/7 Online Chat. Peer Support Groups.

<http://www.rgps.on.ca/caregiving-strategies/> Caregiving Strategies is a collection of educational resources that have been developed and/or curated for family and friend caregivers who provide care and support for seniors experiencing frailty. Caregiving Strategies resources include The Caregiving Strategies website, The Caregiving Strategies Handbook and The Caregiving Strategies online course.

<https://www.davisphinneyfoundation.org/resources/every-victory-counts-2017/> Every Victory Counts is a FREE educational curriculum download through the Davis Phinney Foundation.

<https://www.southwesthealthline.ca> Southwest Healthline is a service directory for Health Services across Southwestern Ontario.

<https://www.swsselfmanagement.ca/content.aspx?pageID=595> Powerful Tools for Caregivers is a FREE 6-week workshop for Caregivers. The workshop series contains 6 sessions - each 2.5 hours in length. Workshops are offered in a community setting with groups of 6-15 participants.

SIX FOODS THAT INTERACT WITH YOUR MEDICATION

Written by Alexandra Potvin-Desrochers, Doctorante

Several medications can be prescribed to control the symptoms of Parkinson's disease. It is often recommended that these medications be taken 30-60 minutes before meals, but the reason for this recommendation is often unknown. Several nutrients interact with some medications, which may even interfere with their effectiveness. In moderate amounts, these foods are often harmless. However, when ingested in large or excessive amounts, they can cause changes in the absorption of the medication and even significant fluctuations in your symptoms. Here are six foods and nutrients that may affect the effectiveness of your medication. Before making any changes in your eating habits, consult your doctor or neurologist.

PROTEINS

Proteins are mainly found in meat, fish, eggs, cheese, yogurt, nuts and legumes. These compete with levodopa (i.e., sinemet, sinemet CR, stalevo, duopa, levodopa/carbidopa, inbrija, parcopa, rytary) since they are absorbed in the same part of the intestine and use the same transporter to the brain. Therefore, it is possible that the levodopa is absorbed less, and therefore you may feel less its effect or have a slower onset of effect when protein is consumed at the same time as your medication. It is important to note that you should not stop eating foods that contain protein, as it is essential for the proper functioning of your body's cells. If you experience fluctuations in your symptoms, talk to your doctor about the possibility of:

- 1- taking your medication more than an hour before meals
- 2- eating most of your protein in the evening (fluctuations will have less impact on your active time of day)
- 3- dividing your protein intake into small amounts throughout the day.



SOFT DRINKS

Soft drinks are to be banned as they contain artificial sweeteners, such as aspartame, which are used for their ability to sweeten without increasing the number of calories. Aspartame is mainly present in so-called light or sugar-free soft drinks, as well as in other foods such as candies, cereals, some yogurts and other drinks (flavoured waters, iced tea, fruit juice). Once in the intestine, aspartame is metabolised into smaller molecules, including phenylalanine. This molecule competes with levodopa to be absorbed by the intestine and interferes with the transport of dopamine in the brain. This increases the time it takes for your medication to be effective and reduces the ability of neurons to release dopamine.

It is therefore advised that you not consume soft drinks or any other food containing aspartame while taking your medication.



VITAMIN B6

Pyridoxine, also known as vitamin B6, is an essential nutrient for a healthy diet. However, too much pyridoxine would reduce the activity of levodopa when given alone (i.e., not in combination with carbidopa). This is rare and mainly concerns the drug Prolopa, which consists of levodopa and benserazide. Vitamin B6 is found in fatty fish (tuna, salmon, cod), offal, poultry, chickpeas, potatoes, bananas, peanuts and whole grain cereals. This adverse effect seems to occur when 50mg and more of vitamin B6 is consumed daily, whereas the recommended daily intake is 1.5mg for women and 1.7mg for men per day for people over 50 years of age. Thus, the harmful dose requires a very large ingestion of vitamin B6, which could be reached if you take supplements of this vitamin or if you eat the foods mentioned above in very large quantities.

IRON

It seems that iron can bind with levodopa and thus reduce the amount absorbed. This would only happen if very high amounts of iron are present in your digestive system at the same time as your medications. This is especially true for people who need to take iron supplements due to another medical condition such as anemia, endometriosis or inability to absorb iron (e.g., celiac disease or gastric bypass). So, if you are taking iron supplements, discuss with your doctor this possible drug interaction and how to balance the amount of iron needed with the impact on your Parkinson's medications.

FRYING

All hard-to-digest foods, especially those high in fat, such as fried foods, creamy sauces, chips and cheese, delay the absorption of medications and can cause fluctuations in your symptoms. Constipation also reduces the effectiveness of medications, so avoid eating foods that cause constipation at the same time as you take your medication.



TYRAMINE

Tyramine is found in foods such as alcohol, aged cheese, deli meats, fermented cabbage and soy products. If you are taking medication called monoamine oxidase B inhibitors, also known as MAO-B inhibitors, such as rasagiline (Azilect), selegiline (Eldepryl) or safinamide (Xadago), it is recommended that you pay attention to your food intake which contains a very high amount of tyramine (more than 150mg). Indeed, these medications could reduce the effectiveness of your system to break down tyramine, and thus increase the concentrations of tyramine in your body. At very high levels, tyramine can cause severe high blood pressure, which should be taken seriously.

REMEMBER TO FOLLOW THESE TIPS

All in all, the important thing is to have a balanced diet while avoiding excessive intake of the above-mentioned foods. Taking your medication at least 30-60 minutes before meals will help reduce possible food and drug interactions. Before making any significant changes to your diet, it is imperative to discuss them with your doctor or nutritionist.

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

ADVANCE CARE PLANNING

Nav Dhillon | Communities of Practice Coordinator, Hospice Palliative Care Ontario

Advance Care Planning conversations help confirm and communicate what quality of life means to you – what values and wishes inform your healthcare decisions. That way your Substitute Decision Maker (SDM) can make future healthcare decisions for you if you are mentally incapable of doing so.

It might take a few tries to get the conversation going and it might take a few conversations. Here are some ideas on how to start having Advance Care Planning conversations (see the Advance Care Planning Guide – For Ontarians at <https://www.speakupontario.ca/wp-content/uploads/2019/11/ACP-Conversation-Guide-Public-Version-Oct-4.pdf>):

UNDERSTANDING

What do you understand about your current health? Do you have any illnesses? What have you been told by your healthcare providers? What do you expect to happen over time? (e.g., Do you expect to get better, be cured or is your illness expected to get worse over time? Might you develop difficulty with memory, swallowing, walking or other things that are important to you?)

INFORMATION

If you have illnesses and are unsure about what might happen over time, what information about the illnesses and treatments would be helpful to you? Is there information that you don't want to know?

VALUES, BELIEFS AND QUALITY OF LIFE

What brings quality to your life? What is important and gives your life meaning (e.g., being able to live independently, to recognize important people, to communicate, to eat and taste food, to spend time with friends and family)?

The remainder of the questions ask you to think about future situations. They are meant for you to consider what might be important to you in the event of a sudden critical illness (e.g., an accident) or as you are nearing the end of your life from a serious illness. This is a chance to tell your SDM about what is important to you and how you would like them to make decisions.

TRADE OFFS

If you become critically ill, life support or life extending treatments might be offered. Describe for your SDM the state you would consider unacceptable to keep living in.

WORRIES AND FEARS

Think about the care you might need if you have a critical illness or if you are near the end of your life. What might you worry about or what fears come to mind? (e.g., struggling to breathe, being in pain, being alone, losing your dignity, depending entirely on others, being a burden to your family and friends, being given up on too soon, etc.)

For further information and resources, go to www.hpcoc.ca and www.speakupontario.ca

JOIN OUR MONTHLY GIVING CLUB

Please consider joining our monthly giving club. Monthly gifts provide a secure funding base for Parkinson Society Southwestern Ontario and lower administrative costs. This allows us to direct more money to our vital services throughout the region.

For more information about monthly giving, please call 1-888-851-7376 or email jessica.halls@parkinsonsociety.ca

RECENTLY I WENT OFF..

Written by Dr. Soania Mathur

Recently I went “off”. For those of you who may not be familiar, in Parkinson’s disease this refers to that period of time during which your medications are not as effective. When that happens, your symptoms return. Which ones and their severity is pretty much luck of the draw. They can be unpredictable and severe, and have a significant negative effect on quality of life for patients, impacting activities of daily living and often leading to social isolation.

For the first decade and a half of my disease, I knew from a medical standpoint what an “off” period was but had never experienced it myself. The next few years brought on a number of “off” experiences which were self-limiting and concerning, affecting my ability to function, but they were still manageable. Then I experienced being “off” in all its glorious severity, giving me an unsolicited look at what this disease, my version of this disease, is like 21 years into the game – and I wasn’t prepared.

Not only were the motor symptoms of stiffness, slowness and tremor difficult to navigate, but the loss of balance and feeling so susceptible to falling was a frightening experience. However, what was most disturbing were the nonmotor manifestations, particularly the depression and anxiety that appeared. My usual optimistic attitude was completely gone, replaced by fear and negative thoughts. My emotions were uncontrollable and my mind created issues and problems when there really were none. My version of reality was skewed and distorted. That was the most difficult and distressing part of this whole experience, not to mention how that loss of self affected those closest to me.

So where am I going with this? Where is the lesson in that experience? Well to be honest, I’m still processing it. My first observation is that this disease is insufferable at times, that it is truly progressive and relentless, leaving no facet of life untouched. But that is not a new lesson learned.

What I also recognize is that as much as we complain about the fact that the gold standard treatment for Parkinson’s has been around for over 50 years, thank the powers above that dopamine replacement exists. Without it, I would not be functional. It is truly life-altering.

What I also recognize is that I am one of the lucky ones. I have access to excellent healthcare and to any of the medications I need. I can afford them and they are readily available. My particular version of this disease is amenable to dopamine replacement. Although there is a fine balance between symptom relief and side effects, an unavoidable daily struggle, I still manage to push through. I am also blessed with a devoted family and life partner who gives me strength to face whatever obstacle I encounter. Not to mention I am surrounded by a strong close-knit community of friends with Parkinson’s whose insight and support I find invaluable and whose understanding and compassion helped me through this particular episode. Truthfully, given my level of functioning, 21 years since my diagnosis, I am grateful for my life.

But I recognize that there are many in this Parkinson’s community who are not so lucky – those who struggle with access to good healthcare and affordable medications, who navigate this journey without the benefit of a reliable and caring support network, and whose lives bend or break under the pressure of this disease. Not to mention those in less developed nations whose plight I cannot fathom.

So yes, this experience has definitely led to some introspection. What lies in my future? Will I be a burden to those I love? What can I do personally to stay the progression of my disease?

But more importantly, being in that severe “off” state has also renewed my sense of urgency and strengthened my resolve, my commitment to this beautiful and vibrant community to use whatever limited skills I may have to hasten the search for better treatments, and ultimately a cure for this disease. It may look like a daunting and insurmountable task, but I assure you that through our collective efforts, we can contribute to a day that the term “off” refers to the lights, not us, and requires a simple flip of the switch.



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.

SING OUTSIDE THE BOX

Written by Cheryl Mazak

There are several structures responsible for speech and swallowing function. The less commonly discussed but highly critical structures involved with these functions are the muscles in the front of your neck, the extrinsic (outer) muscles of the larynx.

Your larynx is responsible for vocal production. Intrinsic (interior) muscles of the larynx adjust the length and tension of the vocal folds, leading to the production and quality of vocal function.

The highly flexible epiglottis is situated above the larynx. The function of the epiglottis is to cover the trachea during swallowing to prevent aspiration of food and fluids and guide them into the pharynx.

During swallowing, the hyoid bone has two muscles attached to it which act to pull it forward and upward. The other attachment site for these muscles is on the lower jaw bone (mandible). This action bulges the tongue which then presses back on the epiglottis, forcing it to close over the larynx and protect the trachea from aspiration.

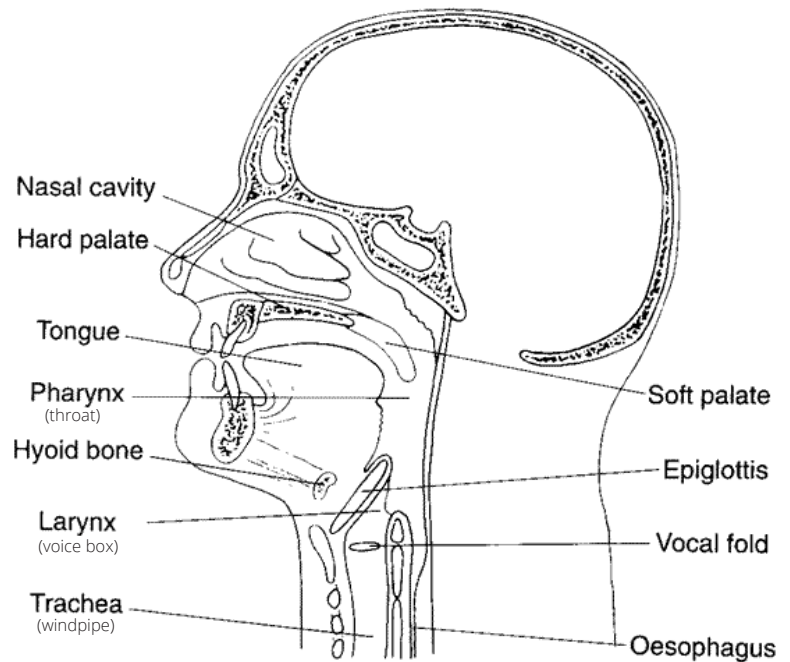
If the muscles attaching to the structures attached to the epiglottis become tight and pull the larynx forward, it may compromise the inertia of the action required for a full seal of the epiglottis.

Combined with regular activities of daily living where we are flexing our heads and shoulders forward, people with Parkinson's become increasingly forward-flexed over time, which decreases the space between the chin and chest. This compresses the structures in the front of the neck and you're going to have more restrictions during swallowing.

If you were to bring your chin close to your chest, exaggerating flexion in the front of your neck and then try to speak or swallow, you should be able to feel the restrictions instantly. It does not make it impossible, but certainly more challenging.

Increasing the space in the front of the neck by lengthening those muscles will take a certain amount of pressure off the laryngeal structures. Most body systems become less efficient when they are in varying degrees of compression. The larynx is no exception.

If you move the larynx in a living body from side to side, the sound production will change, as will the ability to swallow. When there are muscle imbalances on either side, above or below the larynx, it will change the natural position of the structures. This can directly affect the optimal function of these structures.



Head positions illustrating the contrast in space in the anterior neck during 1. flexion, 2. neutral, 3. extension

It can affect pitch, clarity, volume and ease of swallowing.

In the four years that I have been stretching and lengthening the laryngeal muscles in my practice, there has been a direct relationship between these soft tissue structures and improvements on the functions of speech and swallowing.

Parkinson's medications have not been known to cause much (if any) improvements to speech and swallowing function. Stretching and manual manipulation intervention can be an effective way to lengthen muscles and reduce compression on the laryngeal structures.

There are many factors that affect speech and swallowing function. Not all can be improved by soft tissue lengthening. There are many instances that require a Speech/Language Pathologist or the intervention of an ENT (Ear, Nose and Throat) specialist. Obtaining differential diagnosis while seeking soft tissue treatment is critical to the possible outcomes for each individual. Although not a cure for speech and swallowing function, preventive soft tissue manipulation in early stages can help promote optimal function and upkeep of gains.

Information collected is based on independent case studies, research and the collection of anecdotal evidence.

Cheryl Mazak is a 1996 registrant with the College of Massage Therapists of Ontario and training from the D'Arcy Lane Institute. Her treatment approach is outcome-based,

cross-fibre muscle lengthening techniques focused on the muscles of speech, swallowing, respiration, anterior neck and TMJ (Temporomandibular Joint Disorder).



POSITIVITY IN UNCERTAIN TIMES

Kathie Donovan

In this extraordinary time, are you feeling unsettled or uncomfortable? I know I am.

For many of us, this disturbing feeling is a reflection of what's going on in our world, where we don't know much for sure. The fundamental fear we're experiencing has an important role to play for our survival and protection.

However, fear is a trickster. It can make us do and say strange things. Let's not ignore or repress fear. Rather, let's call fear out and face it head on. Let's get clear about what we're really afraid of, and name it. If we're afraid of getting sick, remember that none of us is in charge of the novel coronavirus, only of our thoughts about our own wellness. So, a better focus for our thoughts would be on our wellness, right? The idea of naming what we're afraid of takes away some of its power and puts us in charge of our thoughts, words and actions.

Calling out fear, the con-artist, helps us gain perspective, enabling us to navigate with compassion, empathy and kindness for ourselves and for everyone around us. It's my view that these qualities are our true nature. However, when fear takes over, we overlook them because we go into survival mode and focus on our primal needs. When we ask fear to take a back seat, we create space for our superpowers or empathy, compassion and kindness to support us in managing our fear.

Compassion arises when we feel for someone in a challenging situation without experiencing it ourselves. Empathy flows when we put ourselves in someone else's shoes and feel the experience they're having. In this unprecedented time, empathy is everywhere because we are all experiencing the same threat, so we can appreciate how others feel. Both of these beautiful human qualities come quite naturally to us, but when fear is present, we have to make an extra effort to lead with them rather than leading with fear.

"If you want others to be happy, practice compassions. If you want to be happy, practice compassion."

- Dalai Lama

"I choose the path of kindness. The more you extend kindness to yourself, the more it will become your automatic response to others." - Dr. Wayne Dyer

If you bump up against a challenge with another person in either their behaviours or something they say, remind yourself that, just like you, this person is doing their best to do their best. Call on your endless supply of kindness and compassion to help you navigate and be mindful of your words. If what you want to experience from others is kindness and compassion, make the first move and watch what happens.

Just like the coronavirus spreads in ways we don't fully understand, kindness spreads too. An investigative team from the World Health Organization placed the reproduction number of the novel coronavirus at between two and 2.5. This means that every person who spreads the virus spreads it to as many as 2.5 people. It's been said the contagion factor for an act of kindness is five, which means that every act of kindness impacts five people and when we multiply, just like compound interest, kindness can be a very powerful force.

"We can't control the wind but we can adjust the sails."

We can't personally control the virus but we certainly can control our thoughts and face our fears head on. When we focus on how we can be of service in a very positive way to others, there's no end to what we can do to make a difference.

Acts of kindness can be as simple as smiling, writing a note, making a phone call, giving someone a compliment or simply listening. Remember how kindness spreads and how good you feel when someone shows you kindness. Then ask yourself how you can get busy ensuring we have more than enough kindness to go around.

So, what else can we do to help ourselves and our community? First of all, it's important to be informed, but equally important to not allow ourselves to become overwhelmed. Watching news all day is not good medicine for us on any level. So check in, but don't stay too long. Change the channel ... but to what?

How I'm managing my stress during these uncertain times.

I'm minimizing exposure to drama in the media and in conversations with other people. Be a leader and control the dialogue. Yes, it is scary, but let's all do our best to stay in the present and not get too far ahead of ourselves.

I don't mean to disregard reality, but it's important to surround yourself with positive energy and give your thoughts a positive focus. It could be watching a funny movie, cat videos, uplifting interviews or speaking with people you know who are positive. It can also help to read articles like this to stay focused on what you can do to help yourself and those around you.

It's important to stay connected to one another, and technology provides us with so many options. We can stay 'in community' without having to be irresponsible. The elderly are our most vulnerable. If you think of someone who may need some groceries or a meal, call them and make the offer. Just the sound of a happy voice will settle them down. I'm sure they will appreciate knowing they are not alone in this.

Ask for help if you need it. Believe me, someone is waiting for you to ask.

Thanks to online ordering, electronic banking and all the delivery services out there, we should be able to get what we need, even if we are self-isolating.

Watch your caffeine intake – it can create anxiety in the body, and we want to minimize that. Choose herbal tea or water instead. Make sure you're eating a healthy diet, which means minimal refined carbohydrates, especially sugar.

Practise or learn how to use your breath to calm your body. Meditate to calm your thoughts and body.

Watch the negative self-talk and potential criticism of others. As we've seen, fear is a trickster. It can make us feel like we're doing the right thing when in truth, the right thing is always to be kind to ourselves and everyone else.

Finally, use your thoughts to focus on gratitude for people on the front lines of this virus – gratitude for their service and courage.

I'm grateful for them and I'm grateful for you. Be well; live well.

Kathie Donovan is an author, expert on happiness and wellness ambassador for Nautical Lands Group of Companies. Huron Perth Boomers – Summer 2020.

SWALLOWING AND FEEDING TIPS /STRATEGIES FOR DEMENTIA

Written by Sarah Awde

Please be advised that these are general suggestions. Be sure to seek out a formal clinical swallowing evaluation with a registered speech language pathologist (SLP) trained in dysphagia management (dysphagia = swallowing disorder).

PREPARING FOR A MEAL

If possible reduce auditory/visual distractions during mealtimes (e.g., loud radios, TV, noisy visitors, etc.) You want as much focus as possible on the task of eating/swallowing safely.

Ensure your loved one is sitting as upright as possible for the meal (ideally in a chair). However if bed-bound make sure they are propped up as high as possible. Most important is that the chin is tucked slightly down towards the chest. This reduces the risk of food/liquid prematurely spilling back into the throat. Placing a small rolled towel behind the neck to gently prop the head/neck forward and slightly down can help.

Make sure all sensory aids are in place (glasses, hearing aids, etc.). Dentures should be freshly cleaned and secured well in the mouth. If dentures are extremely ill-fitting, it is best to leave them out and downgrade to a smoother texture until they are properly refitted.

SELF-FEEDING AND ASSISTED FEEDING

Present only one or two food items at a time. Many items at once can be cognitively overwhelming.

If within their ability, continue to encourage the person with dementia to feed themselves, but monitor to ensure small bites/sips are taken. If independent self-feeding becomes difficult, a gentle hand-over-hand tactic works wonders.

The brain will get a BETTER signal if the person with dementia is in any way involved in feeding themselves. Your own hand coming towards your mouth is a long-ingrained pattern that tells the brain (open your mouth, food is coming, prepare to chew ... swallow! etc.).

Being fed by someone can feel invasive and often causes people to “clam up” and “refuse”. If you are getting this response, try the hand-over-hand method along with gentle verbal cues - “John, we’re having a spoon of yogurt now..”, “this is a bite of chicken”. I’ve seen this work WONDERS over the years!

FOOD TEXTURE MODIFICATIONS

There are many different stages of food texture modification that are possible. If “regular/unmodified” food is challenging, try downgrading meals to “casserole soft” or “fork mashable”. The important thing is that the food is soft/moist and more “cohesive”, (i.e., it sticks together). Usually the most difficult solids to manage are ones that are fibrous (e.g., celery, pineapple) or granular/particulate/flaky (dry seeds/nuts, granola, dry rice, crumbly biscuits/crackers).

Eventually you may get to the point where puréed foods are necessary, but again your Speech Language Pathologist (SLP) can let you know if/when that is necessary.

Another sneaky culprit to watch out for is the **two-textured** or **mixed-textured foods**. These are foods that have both a liquid and a solid component together (e.g., chicken noodle soup, dry cereal with milk, fruit cocktail with syrup, even a really juicy piece of watermelon). The reason these are so difficult is that the mouth has to manage TWO different things at once: chewing and keeping the solid bits in a formed bolus whilst trying to control the liquid portion from prematurely falling back into the throat. This is a highly cognitive task that is beyond many people in the moderate to later stages of dementia.

So what can you do? You can either avoid these items altogether (i.e., choose broth or cream soups, drain the liquid from the fruit cocktail, etc.) or if you have a very diligent caregiver who is assisting with feeding, you can alternate liquid bites and solid bites. For example when eating chicken noodle soup, the first spoonful would be just the broth and the next one would be just the noodle/veg bits with the liquid drained off the spoon.

LIQUIDS

Let's talk about liquids. It can get to the point where thickening liquids with commercial thickening agents are necessary for safety reasons. However I would not start doing this unless advised by an SLP. Why? They don't feel natural. People tend to take less of them and then run the risk of dehydration. If you're noticing some difficulty with liquids, here are some things to try first:

If sips of liquid are not going well, try offering them on a teaspoon. A smaller volume can sometimes solve the problem.

Ensure you are offering liquids only when the mouth is completely clear of food. Again, this may seem counter-intuitive. Most people would think to offer a sip of liquid to help get the food down, right? Well, think back to the two-textured food problem. We are trying to avoid having liquids and solids in the mouth at the same time. It's better to encourage clearing the mouth of food, then offer a small sip of fluid.

If they need something moist to help clear a dry item, offer instead a spoon of applesauce or yogurt - these have a natural thickness that will be easier to control in the mouth.

Try offering "naturally" thicker items with meals, like smoothies, tomato juice or chocolate milk.

As a last resort, keep thin liquids separate from food. Offer them in between meals on their own (not with any food). The rationale for this is that if a bit of liquid is going to go down the wrong pipe (this is called "aspiration"), at least it won't take a piece of food with it into the lungs.

ORAL CARE

One of the most important habits to implement is diligent oral care. This is the most protective thing you can do to prevent aspiration-type pneumonia.

Mixed Textures

Why are they so tricky?

Also referred to as "two-textured foods", these food items can be the most challenging for individuals with Parkinson's to swallow.

Why is that? These are foods that have both a liquid and a solid component together (i.e., chicken noodle soup, dry cereal with milk, fruit cocktail with syrup or even a juicy piece of watermelon).

The reason these are so difficult is that the mouth must manage two different things at once: chewing and keeping the solid bits in a formed bolus while trying to control the liquid portion from prematurely falling back into the throat.

We know that with Parkinson's, initiating and controlling movements can be impaired. Well, this is also true for the mouth and throat muscles. When liquids and solids are introduced to your mouth at the same time, it's kind of like trying to pat your head and rub your belly at the same time. It's more challenging.

Does this mean that you have to avoid all of these yummy two-textured food items? Not at all! There is a simple solution. Alternate spoonfuls of a) just the liquid portion of the item (e.g., just the broth in a chicken noodle soup) with b) spoonfuls of just the solid bits (liquid drained off). This eliminates the issue of putting two different textures in your mouth at once.

For additional protection, keep your chin tipped slightly down when the food/liquid is in your mouth. This allows gravity to keep the bolus in the front part of your mouth, reducing the risk of premature spillage into your throat before you are ready to swallow. NOTE: this is not the "chin tuck posture" you may have heard speech therapists refer to before. That is a much deeper posture that is recommended for certain people with swallowing issues to increase airway closure during the swallow.

Lastly keep in mind that taking pills with water is considered a mixed texture! Many people struggle with taking pills for this very reason. An easy solution is to take pills singly coated in either apple sauce or yogurt. The pill will be much easier to swallow and you can always chase it with a small sip of water once the pill is down.

Bon Appétit!

As always, if swallowing issues for you or your loved one are persistent, seek out a formal swallowing evaluation with a speech language pathologist.

Did you know that the real culprit for this type of pneumonia is not the food or liquid entering the lungs? The food and liquid are merely the vehicles for the mouth bacteria to enter the lungs and colonize.

Remember a cleaner mouth = cleaner lungs. You cannot do enough oral care. Especially just before a meal and just after.

MEDICATIONS

Unfortunately, many people with dementia are on numerous pills/tablets. Some are massively sized or non-coated and can be difficult to swallow. If swallowing meds is a problem, ask your pharmacist or doctor if the medication comes in an alternate form (a syrup, smaller coated tablet, etc.) or if it is crushable. Some meds are not crushable as they are "extended release". Always check.

Swallowing pills with water can be tricky. Again remember the difficulty with two textures in the mouth. Always give one tablet at a time, slowly.

Try coating in applesauce, pudding or yogurt as these are more cohesive, move more slowly in the mouth and help pills slide down. They can also help mask the yucky taste of crushed meds.

Always check inside the mouth to ensure the pills have been swallowed and aren't hiding in a cheek pocket, under the tongue, etc.

If you or a loved one are experiencing any difficulty with swallowing, seek out a formal evaluation with a registered speech language pathologist.

Sarah Awde is an Ontario registered Speech Language Pathologist with over 16 years experience working with adults with every manner of communication and swallowing impairment. She currently runs a private practice called Get LOUD!

Therapy, working exclusively with individuals with Parkinson's disease. Sarah is thrilled to partner with PSSO to offer online LOUDER CLEARER PD voice exercise classes.



Parkinson Society Southwestern Ontario is Your Home for Listening

Comfort: it's the thing that makes us feel good. It can appear in many forms: a perfect breakfast, a lovely memory, knowing things are in order, or a simple accomplishment. Comfort is many things. It is a universal experience and need, but it is highly individual. What does comfort mean to you? When do you seek it and how? Counselling may be a comfort when the usual fixes are elusive. When life feels overwhelming, a little beyond control, or when we feel stuck or alone, a listening ear may help.

"There's a sorrow and pain in everyone's life, but every now and then there's a ray of light that melts the loneliness in your heart and brings comfort like hot soup and a soft bed."

*– Hubert Selby Jr.,
Requiem for a Dream*

Parkinson Society Southwestern Ontario has teamed up with the King's University Social Work department to provide counselling services by students, to our Parkinson's community. People with Parkinson's and their carepartners can access the service for free, either individually, or as a couple. Families are also welcome.

Some of the reasons you might seek counselling could include dealing with a new diagnosis, issues within your relationship, grief and loss, managing life's challenges, feelings of depression or anxiety, or there may be something else on your mind.

How can we help? Sessions will focus on supportive listening, identifying key concerns, processing issues and mutual goal-setting. Exploring your unique strengths and the positive elements in your life will form a foundation on which to build solutions and positive change.

Appointments will last up to an hour and can be provided in person at the Parkinson Society Southwestern Ontario London office, by virtual meeting (Zoom) or by phone. Counselling is offered on a part-time basis through the week during the academic year. It is not intended to deal with crisis situations. If you are at risk of immediate harm to yourself or others, or if you require immediate medical attention, please call 9-1-1.

Parkinson Society Southwestern Ontario is your home for listening. Want to know more? If you have questions or are interested in setting up a counselling appointment, please connect with us! 1-888-851-7376 extension 28 or email at info@parkinsonsociety.ca.



Christine Loop is in her third year at King's College in the Social Work program and recently completed a six-week placement at Parkinson Society Southwestern Ontario.



WALK THE BLOCK

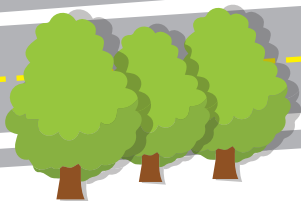
FOR PARKINSON'S

SEPTEMBER 12TH & 13TH

STEP 2

COLLECT DONATIONS

Online donations are preferred but we will accept cash and cheque donations. If you have questions, please contact us at events@parkinsonsociety.ca



STEP 4

WALK YOUR BLOCK!

Join us for an online kick off on September 11th and then walk your community block on September 12th or 13th!

STEP 1

REGISTER ONLINE

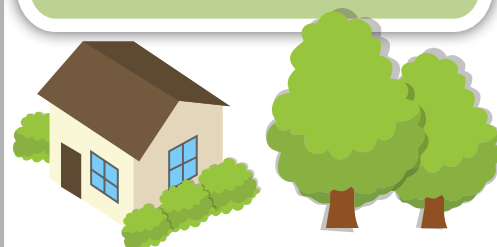
Walk individually or as a team!
Remember, you don't have to be together physically to be a team!



STEP 3

GET CREATIVE, GET SOCIAL

Share with people why you walk! Make a poster and hang it in your window. Post on social media and use the hashtag **#walktheblockpd**



For more information please visit:

walktheblock.ca

WE ARE THE EAGLE FAMILY

We are the Eagle Family. We have two beautiful children, ages 8 and 6 and we live in New Hamburg. We are a very close family. We are also very close to my parents, Mike and Joan. We enjoy our Sunday dinners together and any other opportunity we have to get together with them, like the horse and trolley ride through Waterloo Park at Christmas time or going to the beach as often as possible all summer long! They have always been there for us and have done so much for us over the years. My Mom and Dad have been married for almost 40 years! Their marriage has been an inspiration to us all. Growing up, my siblings and I were so lucky to have a Mom who always cooked us wholesome meals and kept a clean and happy home, while my Dad would always be hard at work at his job or working on a car in the driveway. I have always felt so blessed to have them in my life.



Finding out my Dad had Parkinson's was one of the hardest days of my life. My Dad has always been so strong and never showed much emotion. I can never understand how he felt that day he heard the news. All I knew was I wanted to take any hurt, frustration, anger, anxiety or any other negative feeling away from him. It just didn't seem fair that he had to go through something like this. Someone who has always been such a good person, who would give anyone the shirt off his back, to have to endure something like this was incomprehensible to me. Why him? Why my Dad?

My Dad has always been very active. He has been an avid runner since the age of 29. The news that he had Parkinson's didn't slow him down though. He began running farther and biking three hours at a time. He also began a boxing class at the local YMCA. Exercise is great for helping to slow down the progression of Parkinson's and I am happy to see my Dad working hard to do just that, and extremely grateful that he's able to.

In 2018 my mother-in-law told us she had seen a sign for an event called "WALK- IT for Parkinson's." Naturally, I got online right away and created a team. Doing something that can help raise money for people living with this disease was something that brought me and the rest of my family so much happiness. All the money raised goes toward supporting Parkinson's programs and services as well as research. After our first walk in 2018, I knew we would be going every year. This event allows people to come together and walk for a great cause. It's a lot of fun, especially because there is music, food, drinks, prizes and other entertainment, making it an awesome way to spend an afternoon!

My Dad has always been a pretty quiet person. This has brought him out of his shell a little bit, and to see him connect with so many others who are going through the same thing warms my heart! The walk does so much more than just raise money. It creates a support group for those going through it and really helps people like my Dad to not feel alone.

I was recently approached by the head coordinator of the annual walk and was asked to join the committee. I had thought about getting involved but didn't know how. This committee lets me give back by helping to plan an event that helps so many people. It's a great group of people to work with and I look forward to working with them every year!

There may not be a cure yet, but hosting these events and having all these wonderful people support the cause gives us hope and gets us one step closer to finding the cure!

My Dad, like everyone else suffering from this disease, has had his tough moments. But he is doing the best he can to work through it. He is the kindest, most caring, most helpful man you will ever meet. I am so proud to call him my Dad!

*Even though we can't come together the same way this year, people like the Eagle family will be walking their block on **September 12th & 13th for WALK THE BLOCK for Parkinson's.** For more information, go to **walktheblock.ca**.*

VOLUNTEER PROFILE – DEVIN BOX

When he was young, Devin Box's father gave him some wise advice. He said, "People are not going to remember you for what you did, but they will remember you for how you made them feel." Those words resonated with Devin and became the foundation for how he now lives, works and connects with the community.

A Western University student and future doctor, Devin is grateful for the support of his two mentors, Dr. Jayne Garland and Dr. Mary Jenkins, who pointed him toward Parkinson Society Southwestern Ontario (PSSO) when he was looking for volunteer opportunities where he could build relationships and experience the impact of human connections that cannot be learned from a book.

His work with PSSO began just a few weeks before COVID-19 arrived where he jumped into the role of facilitator for the London Parkinson's support group. Through the support group, his learning continues. He has met incredible people and he listens with care and compassion to the successes and challenges of their unique and individual journeys. Devin states, "I want to use my experience and my education to lift others up, to help out and to make a difference. It is essential to me that people realize they are important and valuable, and I want their experience to be full of positive energy and support."

By March, the support group moved to an online platform. This can often present challenges for larger groups to communicate. So far, the process is working well. These virtual meetings still offer support, discussions continue to be engaging and participation is growing.

To help ensure the online version was providing what participants wanted, Devin sent a survey to gain insight on the topics that the group would like to explore each month, along with asking what they wanted to see from him as their facilitator. He offers, "People's needs given this pandemic may have changed and I want to be sure we are bringing forth all the right information for this group." Devin is excited to be sharing the stage at the June support group with Nelson Sleno. Nelson is the author of *Shaking Hands*, which is a chronicle of his inspirational personal journey, one Mr. Sleno calls a "road-map to guide family and friends whose lives are indelibly altered by this disease." Devin's plan is to continue to provide varied and relevant information each month to all participants of the London Parkinson's support group.

Devin shares that volunteering with PSSO has opened his eyes to the genuine nature of medicine versus the competitiveness of the classroom. He understands why medical schools want people who are committed to both their communities and the people who live there. When he asks himself, why is it he wants to be a doctor, the answer that always comes back is an unequivocal, "because of my passion to serve others."

Devin plans to stick with his volunteer role at PSSO and is also happy to pitch in and help out with whatever the needs are, even if he's a little unsure of what he might be getting into. He wants to make a difference. He enjoys working with the PSSO team and learning how to successfully provide support through a pandemic. He shares, "I'm in the right place right now for my life and I believe everything happens for a reason. I'm learning new skills, sharing fresh experiences and I am grateful for all the people I have met."

It sounds like his Dad might just be onto something. There's a very good chance that people will always remember Devin for how he makes them feel.



Written by Cheryl Losch, Volunteer, London

In Memoriam

We offer our sympathy to the families whose loved ones have passed away between January 1, 2020 and June 30, 2020.

Terry Adams
Carolyn Arnold
Barry Athoe
Peter Barnes
Mike Barr
John Basque
William Beattie
Nancy Bergamin
Millie Blackwell
Douglas Bondy
Larry Bossence
Paul Bottineau
Yolanda Bowyer
Ethal Mary Brennan
Janet Brockway
Jack Brooks
Bill Broome
Clare Brown
Don Brownlee
Doreen Burd
Bobby Burks
Margaret Burnes
Mary Lou Burnett
John Carlson
Glen Carson
Robert Carswell
Lawrence Cassin
Gail Chalmers
Earl Clemens

William Cluff
Lorraine Cochrane
William Crow
Gerald Dale
Dirk de Jong
Kathleen DePratto
Rose Desjardins
Raffaele DiFederico
Kent Dixon
Melvin Doughty
Shirley Durocher
Frances Ebbinghouse
Stuart Ellis
Ken Featherstone
Ken Fitchett
Dennis Fletcher
Hugh Fonseca
Robin Gale
Almeda Gervais
Keith Gill
Duncan Gillies
William Gilroy
Alan Greenfield
Frank Guarasci
Jerry Hagen
Paul Haller
Ralph Hall
Barbara Hamlin
Neil Harris

Mary Herron
Carol Hillier
Carla Houtman
Jan Huisman
Donato Iacovone
Helen James
Maria Kampain
Marie Kavahagh
Marion Kiddie
Crystal Lainey
Yvonne Lambert
Wayne Lee
Wayne Little
Sally Livingstone
Irma Lombardi
Rino Longo
John Lounsbury
Hugh MacDonald
Frances Marsman
Beverley Marzoli
Valanne Mascotto
Peter Maxwell
Frances McCallum
Robert McFaul
David McGlynn
Kelly McMaster
Ross McTaggart
Beverley McTaggart
Donald McTavish

Peter Merkel
Carl Mills
Thomas Milner
Patricia Mitchell
Rena Mole
Brendan Morgan
Joe Moser
Harry Moyer
Robert Muir
Roy Murphy
Richard Nagle
Stephen Napper
Philippa Newcomb
Christine Newman
Aleida Nooren
Matthew Owen
Ron Penwarden
Lester Phillips
Julie Predki
John Pye
Theresa Reynolds
Donald Robitaille
Ronald Ross
Vincenza Rossini
Victor Sartori
Josef Schaffer
Chuck Schiedel
Giovanni Sementilli
Sally Shantz

Bruce Shaw
Paul Somers
Joyce Spencer
Audrey Strong
Betty Sutton
Helena Thiessen
Brian Tilotson
Douglas Tuck
Harold Vail
Manfredo Valente
Maria Van de Mierden
Stanley VanderWal
Ernest Verbraecken
Michael Verrier
John Vincent
Nelda Vollans
Raymond Walker
Bill Ward
Stuart White
Shirley Whitney
Jack Wilde
Edward Wilkinson
Mary Woods
Joanne Wright
Kathryn Yager
Fred Zylstra

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.

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.

VISIT [PARKINSONSOCIETY.CA](https://parkinsonsociety.ca) AND FIND OUT ABOUT:

- Parkinson Society Southwestern Ontario and our services
- Parkinson's and Parkinson's programs
- Upcoming events, conferences and workshops
- How you can help
- Corporate/Employee involvement
- Signing up on our mailing list
- And more ...



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for the most up-to-date Parkinson's related information

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