SPRING ISSUE 2021

MDC CONNECTIONS

Helping you maintain momentum with powerful resources is our priority.

What's inside:

April is **Parkinson's Awareness** month!

Learn about Parkinson Canada's "No Matter What" campaign *p.8*

Hear from our experts! Register for the 2nd virtual **UHN Speaker Series** *p.4*

Read our COVID-19 **vaccine** statement *p.5*

Mental wellness check-in

Apathy explored with Dr. Zurowski *p.15*
Mental wellness resources *p.18*
Virtual support communities *p.21*
Self care reminders *p.24*
Mindfulness *p.26*

Welcome

Welcome to the second edition of *MDC Connections* — a newsletter series of resources to inspire you to do more, to move more, to learn and to conquer. Empowering you and your loved ones with information and offering ways to connect.

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Please note that the listings below include events not organized by the Movement Disorders Clinic, the Integrated Movement Disorders Program, the University Health Network, and organizations with which they are not affiliated. Any listing of third-party events or programs should not be considered an endorsement. We cannot be held responsible or liable for any loss or damage suffered as a result of participation in third-party events and programs.

UHN Movement Disorders

Supported by the Edmond J. Safra Program in Parkinson's Disease

Connections

In a time that continues to evolve with each passing day, we want to share a welcoming of Spring with you - here's to a gentle gesture, a calm embrace, a soft warm breeze. As we ease into - should we say - a 'new phase' of pandemic life.

Know that we are here for you. You are not alone.

April is **Parkinson's awareness month**, dedicated to placing Parkinson's front and centre all over the country. Join us in creating a stir in your community and the world at large. Engage in the fight against Parkinson's by learning and sharing as much as you can. Take a look on page 8 to learn about and register for Parkinson Canada's virtual event happening at the end of this month. Help elevate greater public awareness and understanding, and turn that dial toward prioritizing recognition, urgency, research and change.

We are excited for this *MDC Connections* Spring issue that focuses on mental health and wellness. Mental wellness is a challenge that touches everyone, especially now. Because of the global pandemic, the critical importance of mental health is now front and centre. It is a key determinant of overall health, and is especially relevant in movement disorders. Strategies to maintain good mental health allow you to feel, think and act in ways that help you enjoy life and cope with challenges. We've collected and curated some of these strategies in this issue.

Please share this newsletter with your spouse, care partners, friends and family, they may find some useful wellness strategies for themselves, or something of interest!

We wish you and yours a healthy and restorative season. The return of the light, warmth, spring showers and blossoms reminds us to embrace our own recharging practices that nourish our hearts and minds. Get outside, move more, reach out and connect with yourself and with others. We all need it.

Julie Racioppa, Editor

We value your feedback!

We are grateful to have made it into your inbox, inviting you to connect in new ways. We are a small but passionate team and the feedback we receive from you makes everything worth the effort.

Feedback!

If you would like to provide feedback about this newsletter please click this link to complete a short survey or email us your comments at: movementdisorders@uhn.ca

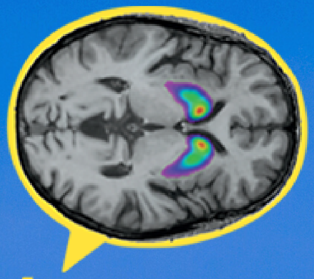
Share your story!

We would love to share your stories, tips, recommendations, anecdotes, testimonials, research experiences, photos or artwork in this newsletter! Email us at: movementdisorders@uhn.ca

> *"You cannot look in a new direction by looking harder in the same direction."*
> ~ Edward de Bono

Upcoming Event!

UHN Movement Disorders Speaker Series ***Virtual Event***



We look forward to hosting for you the 2nd virtual edition of the ***Movement Disorders Speaker Series: Making Patients Partners***, taking place via livestream on:
Wednesday, April 14 from 2-3 pm.

As part of the Integrated Movement Disorders Program (IMDP), the Patient Advisory Board's mission is to advise on innovation in research and treatment at the Toronto Western Hospital Movement Disorders Clinic, one of the worlds leading Parkinson's centres. This can range from setting treatment policies to what research could enable in the future.

The PAB is comprised of patients, caregivers, and faculty, allowing for diverse approaches and discussions between members.

This *Speaker Series* edition will focus on the PAB, what it strives to achieve, its impact on patients with movement disorders, and how you can help and support this group to fulfill their mission.

Please join us for the 2nd virtual *Movement Disorders Speaker Series* Live Stream presentation and Q&A moderated by Christian Coté, host of UHN's Behind the Breakthrough podcast, and with special guests:

Dr. Anthony Lang, Director, Edmond J. Safra Program in Parkinson's disease; Director, Morton & Gloria Shulman Movement Disorders Clinic

- **Dr. Sarah Lidstone**, Director, Integrated Movement Disorders Program
- **Hugh Johnston** (CPA, CA retired),Chair, PAB
- **Soania Mathur** (MD), Co-Chair, PAB
- **Gordon Myers**, Chair of Communications, PAB

CLICK HERE TO REGISTER

Once you register, you will be able to submit questions for our guests in advance.

Toronto General & Western Hospital Foundation UHN | WHAT KNOWLEDGE CAN DO

COVID-19 Vaccine Statement

COVID-19 Vaccination in Patients with Parkinson’s disease and Movement Disorders March 22, 2021

There are currently several highly effective vaccines approved for COVID-19 available in Canada. Persons with Parkinson's disease (PD) are encouraged to be vaccinated unless they have other health concerns that make the vaccine inappropriate for them (see Ministry of Health guidance, or speak with your Family Doctor). It is recommended that patients come forward to seek the vaccine as quickly as it is available. There is no evidence that people with PD should receive one vaccine over another. It is best to receive whichever COVID-19 vaccine becomes available to you. The benefits and risks of receiving this vaccine are no different than in the general (age-matched) population. This vaccine is not known to interfere with the current PD therapies. These recommendations and conclusions can also be extended to patients with other movement disorders. This includes those with dystonia as there is no reason to believe there would be a higher risk of side effects with these patients, even if receiving botulinum toxin treatments.

What is known about the use of COVID-19 vaccines in PD?

1. The approved mRNA-based vaccines and the vector vaccines under development induce immunization through mechanisms that do not interact with the neurodegenerative process in PD. With respect to the associated inflammation in the pathogenesis of PD as we understand it today, there is no evidence of any interaction with the immune response to these vaccines.

2. The reported Phase III data of the approved vaccines showed that the types or incidence of side effects in patients with PD have not been different than in the general population.

3. Similar to reactions to other immunizations, COVID-19 vaccination does not interfere with the current therapies of PD.

4. As some of our patients may be part of the first groups in the current vaccination programs because of their age, residency in nursing homes, or other reasons related to PD disabilities, more data will be available in the near future for further analysis of the impact of these vaccines on PD.

COVID-19 Vaccine Statement continued

What side effects are expected?

Common side effects are pain, redness, or swelling where the needle was given, tiredness, headache, muscle pain, chills, joint pain, and fever. You may also experience nausea, diarrhea, or swollen glands in your underarm.

After I receive the vaccine, do I still need to practice social distancing and wear a mask?

Yes, everyone who is vaccinated will still need to follow ALL established public health measures on physical distancing, mask wearing, and washing hands etc. This is because we know the vaccine protects against COVID19, but we do not yet know how long the protection lasts and whether it prevents transmission to others.

Still have questions?

Please speak to your Family Doctor if you have any further questions about your personal health history as it relates to the COVID-19 vaccine.

Resources

Ministry of Health COVID-19 Vaccination Recommendations for Special Populations https://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/vaccine/COVID-19_vaccination_recommendations_special_populations.pdf

International Parkinson and Movement Disorder Society-MDS COVID-19 Vaccine Statement for Patients https://www.movementdisorders.org/COVID-19-Pandemic-MDS/MDS-COVID-19-Vaccine-Statement-for-Patients.htm

Parkinson Canada https://www.parkinson.ca/covid-19-and-parkinsons/?highlight=covid%20vaccine#question1Answer Michael J. Fox Foundation COVID-19 Resource Hub

News in Context for the Parkinson's Community: What We're Learning about COVID-19 Vaccines https://www.michaeljfox.org/news/news-context-parkinsons-community-what-were-learning-about-covid-19-vaccines

Dystonia UK COVID-19 Vaccination https://www.dystonia.org.uk/news/covid-19-vaccinations

Parkinson's Foundation Center of Excellence Sheds Light on COVID Vaccine and Parkinson's https://www.parkinson.org/blog/science-news/COVID-Vaccine

COVID Resources

Check for the latest news and updates on how UHN is keeping you safe with changes to services, policies and vaccine information.

Read more about Virtual Care at UHN.

Stay informed. Know when, where and how to get tested and when to stay home.

For current news, restrictions and guidelines to keep you safe and in-the-know.

*10 facilities with fitness centres and walking tracks are available throughout lockdown to individuals with disabilities. Reservation only.

How Ontario is responding to COVID-19. Includes case data, testing locations, and a self assessment tool.

COVID-19 current situation, risk, updates and how Canada is responding**.**

Need a break? Toronto Public Library is here for you! For entertainment, boredom alleviation and endless learning. You don't need a library card to access their wealth of resources.

They have BBC Literary adaptations you can watch online!

Parkinson's Awareness Month

April is Parkinson's Awareness Month - dedicated to raising awareness of Parkinson's.

"No Matter What" is a video rallying cry for Canadians living with Parkinson’s, celebrating resilience, strength of spirit and perseverance.

Nothing prepares you for Parkinson’s, but life goes on: No Matter What. Join our speakers who share what resilience means to them and specific strategies for living well with Parkinson’s. There is strength in numbers, there is hope in research, and there is support all around you.

Hosted by a special guest keynote speaker, Larry Linton, Dr. Naomi Visanji, and Hugh Johnston share their unique perspectives on life with Parkinson’s.

- Larry Linton is the chair of the Parkinson Advisory Council with Parkinson Canada and is the author of Shaken, not Stirred: Living with Parkinson’s Disease. He’ll expand on his experience with diagnosis, and what he knows now that he wishes he did the day he learned he had Parkinson’s.
- Dr. Naomi Visanji holds an appointment at both the University of Toronto department of Laboratory Medicine and Pathobiology and Edmond J. Safra program in Parkinson's disease at Toronto Western Hospital. Dr Visanji’s research focuses on the pathobiology of alpha synuclein in Parkinson’s disease including the detection of peripheral alpha synuclein as a biomarker. She’ll talk about the importance of diagnosis, and what No Matter What means as a researcher and daughter of someone with Parkinson’s.
- Hugh Johnston is a founding member of the PD Avengers and Chair of the Toronto Western Hospital Movement Disorders Clinic Patient Advisory Board. He’ll share his perspective on making Parkinson’s matter and why advocacy efforts are so important to our collective resilience in the face of Parkinson’s.

Join Parkinson Canada on April 29 at 1PM ET for this 90-minute panel discussion. Learn more and register at www.parkinson.ca.

~Jon Collins

Resilience Webinar: Perspectives on Living Well with Parkinson s: No Matter What

"It crept up on me"... researcher diagnosed with Parkinson's shares his story

Every day, 25 Canadians are diagnosed with Parkinson's Disease. In 2015, Dr. Harold (Harry) Robertson was one of them, but his path to diagnosis is unlike many others.

Harry's journey to diagnosis started in 2009. Having studied the effects of dopamine on brain disorders such as Parkinson's and schizophrenia for years, he took an interest in 2009 in preclinical markers for Parkinson's. In particular, he was looking for those that might lead to an early Parkinson's diagnosis as the key to start treatment before the onset of symptoms. Specifically, Harry was interested in the loss of smell as a predictor of Parkinson's. In his research, he found that changes to the olfactory bulb could occur five-to-ten years before the onset of motor and other symptoms.

During the study, Harry reflected that he, himself didn't have a good sense of smell. Like so many, he did not think much of this until other Parkinson's symptoms began to show. Six years later in 2015, he developed a mild tremor in his left hand. Then, one day he had some difficulty climbing the stairs at a friend's cottage. Armed with all he knew, Harry saw a neurologist and was diagnosed with Parkinson's.

"It crept up on me," Harry reflects. "The symptoms were very mild in the beginning. They were hardly noticeable." Having been around Parkinson's for years, he understood the diagnosis well. And he was determined to stay positive.

The reality is that a diagnosis of Parkinson's creeps up on a lot of people. If a researcher studying early signs of Parkinson's took many years to receive a diagnosis, you can imagine there are many more who aren't diagnosed until more prevalent symptoms begin to show.

This Parkinson's Awareness Month, Parkinson Canada is highlighting stories of difficulties in accessing care and delayed diagnosis to generate public awareness of this challenge that can have significant mental and physical health impacts for the person with Parkinson's, and ultimately delays treatment.

Read more about Harry's story and what you can to do support greater access to care in this month's Parkinson Post (scheduled for April 21).

Tech Help!

This e-newsletter is made for technology! It works best if you view it on a computer, laptop or tablet. Links to resources are embedded. Anytime you see something **bolded** or underlined try clicking it to take you to a website!

Virtual Visit help g

UHN has important tips
preparing for a virtual v
For more information ch

We, the **Movement Diso**
has a quick guide here
and more details here.

Ontario Telemedicine Network (OTN) troubleshooting and help guides are here.

New to technology?

Toronto Public Library offers free computer classes - from learning the basics to Microsoft Office and digital design. Check out their course offerings here.

5 Reasons to keep up with technology

1. Technology fosters independent living - think medication and activity reminders, fall detection devices, smart watches and smart appliances that turn off automatically.

2. Technology connects family and friends with one another - strengthen connections with instant text messaging, video calls - Zoom, Skype, Facebook and other social media.

3. Technology keeps you engaged and entertained - Netflix, Tubi, YouTube, gaming.

4. Technology helps you stay informed - ensure your sources are reputable.

5. Technology enhances your productivity - try shared calendars and bookmarking.

App Alert!

Apps are a great way to try out something new and connect with others. Be it a new activity, a zen inducing breathing technique, a therapy session or brain teaser! Challenge yourself and see where it takes you!

For Relaxation:

Calm

This mindfulness app includes nature photos and calming sounds, as well as guided meditations.

For Activity:

PARTICIPACTION

Fitness and exercise app designed to get you moving. Research-based, rooted in behaviour change science, designed for Canadians by Canadians.

For Wellbeing:

AbilitiCBT
by Morneau Shepell

iCBT is internet based cognitive behavioural therapy. Combining a personalized therapist-guided program with digital tools and exercises.

For staying sharp:

lumosity®

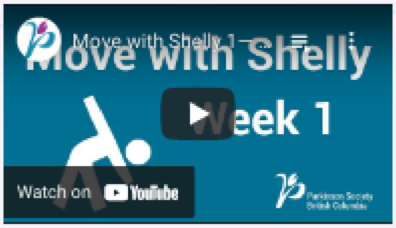
Brain training! Games to help improve memory, attention, flexibility, processing speed and problem solving.

Move that BODY!

You don't have to have a movement disorder to take part!

Patient recommended!

Join Shelly Yu, Parkinson Society British Columbia's Neuro Physiotherapist for online Parkinson's exercise classes. Challenge your strength, balance, and mobility, with standing and sitting options for varying levels.



Improve strength, balance, coordination & vocal projection. Use a sturdy chair and a soft small ball or socks.

- Also check Power for Parkinson's YouTube playlist for free exercise, dance and vocal classes.

Neuromotor exercises and physical therapy focused on coordination and balance has been shown to improve the progression of functional decline and is a treatment for Ataxia.

- Also check out 11 Exercises for Ataxia patients.

Activity Guide

Try these!

Start slow

Listen to your body

	LOW INTENSITY	***MEDIUM***	***HIGH***
Aerobic **2 times per week**	BREATHING IN FLOW	BRISK WALKING	BIKING- STATIONARY OR OUTDOORS
Strength Training **2-3 times per week**	HAND EXERCISES	MODERATE AEROBICS	YARD WORK
Balance Training **2-3 times per week**	SIT TO STAND	QIGONG	BOSU BALL
Flexibility **2-3 times per week**	SEATED STRETCHING	GARDENING	FLEXIBILITY YOGA

Alternate therapies

- Qigong (pronounced 'chi kung') is a gentle exercise using mindfulness, breathing, and a precise set of slow and graceful movements.
- Qigong is a traditional Chinese wellness practice with roots in philosophy and martial arts.
- Qigong is a practice to cultivate and balance qi - pronounced 'chi', translated as 'life energy'.
- Qigong is practiced for recreation, exercise, relaxation, meditation, self-awareness, and training for martial arts.
- Qigong increases blood flow and can help with balance, flexibility, lower blood pressure and improve mental health.

Chris Manning, exercise enthusiast and PD patient, finds qigong particularly helpful ~ Eight Pieces of Brocade has been practiced for over 2,000 years. It is said that Chinese folk hero General Yue Fei taught the exercise to his men to help keep their bodies strong and well prepared for battle. "Eight Pieces is ideal for people like me who have lost the mobility needed for boxing or tai chi, particularly as there is also an excellent seated form available on YouTube, I would particularly recommend Qigong Full 20-Minute Daily Routine for anyone who is interested."

Patient recommended!

> *"For me it's been a real boost"*
>
> ~ Chris Manning, PD Patient and Advocate

Apathy

From the Neuropsychiatrist's desk

Written by Dr. Mateusz Zurowski MD MSc FRCPC

There are many neuropsychiatric elements to Parkinson’s disease. These include depression, anxiety, fatigue, sleep problems, cognitive problems, psychosis, and motivational difficulties.

Patients with Parkinson's often have low motivation or apathy. Apathy is frequently more apparent to the partners of patients, it is often less clear to the individuals themselves. **Apathy is defined as a feeling of indifference or lack of interest or motivation in activities as felt by the individual.** Partners witness a behavioural syndrome of decreased self initiated goal oriented activity, meaning that the patient seems to be just sitting around and not doing much of anything. The patient may be aware of not doing anything and have full intentions of doing something, but at the end of the day, each day, nothing much is accomplished, no interesting goals are pursued, no people are contacted, even the partner seems to be ignored. This behaviour is not the result of laziness. It is a syndrome that 20-36% of people newly diagnosed with Parkinson's experience prior to starting their Parkinson medications. As the illness progresses apathy becomes even more common with 40% of individuals without dementia and 60% of those with dementia reporting symptoms after 5-10 years of illness.

Apathy can be broken down into various elements that may be root contributors. These include:

1. Reward deficiency syndrome
2. Depression
3. Executive dysfunction
4. Decreased self-activation
5. Energy conservation
6. Fear of doing something wrong

Often more than one of these elements may be active and contributing to apathy. They are each caused by parts of the brain not working as well as they should.

In the *reward deficiency syndrome*, the individual experiences emotional blunting or absence of emotional resonance preventing the attachment of motivation and pleasure to internal and external factors. Basically, they just don’t have the emotions that drive motivation, and even if they do something there is no pleasure or positive experience from the activity. It is just as easy to do nothing as it is to do something that feels like nothing. This closely overlaps with the concept of *anhedonia*, which is a form of depression in which there is very little pleasure from previously enjoyed activities. These two causes of apathy can be very difficult to distinguish with the intriguing finding that some people can develop a reward deficiency syndrome by taking antidepressants to treat their depression. While others benefit from antidepressants in developing the necessary emotions to drive behaviour. Other overlapping symptoms between apathy and depression include s-l-o-w-n-e-s-s of thinking, moving, and reactivity to events and people. In both instances patients with apathy and depression may be less active and less enthusiastic about the world around them. However, with depression there are often other emotions such as sadness, excessive guilt, negative thoughts, and pessimism about the self, the world and the future. In depression there is often a greater amount of emotional suffering, while apathy is more indifferent and emotionally blunted.

As patients get older and have a longer duration of Parkinson's, they are at increased risk of developing cognitive difficulties that are characterized by *executive dysfunction*. Executive dysfunction affects many cognitive functions including action planning and organization, as well as the redirection of attention from one stimulus to another. It can result in decreased curiosity, getting cognitively stuck, being more rigid in approach to challenges, trouble sequencing tasks that require multiple steps, and uncertainty of where or how to start an activity. In short, people with executive dysfunction may look very much like those with apathy - sitting on the couch and not engaging in pleasurable activities. Those with apathy don't have the motivation, while those with executive dysfunction are motivated but are stuck in the details and uncertainty of where to begin. They also have difficulty in reacting to new opportunities as they are still stuck and working through what they have already started.

Another element of apathy for some is *decreased self-activation*. It is the absence of self-generated thoughts, emotions and behaviours; a mental emptiness. They have nothing to say, nothing to share and nothing seems to matter. Partners report a quiet home, even when sitting in the same room as the person with Parkinson's, there is an eerie silence. The only time the person with decreased self-activation comes to life is with external stimulation, like when a visitor arrives. In those instances the patient becomes almost their old self; talkative, charming, engaged. This leaves the partner puzzled and feeling taken for granted, because the house was quiet and their loved one with Parkinson's could not seem to muster even the most basic of responses one minute, while the next they are up, jovial and participating. This can be very frustrating.

Other elements that can be mistaken for apathy because of decreased activity include patients' desire to conserve energy and their reluctance to take chances with the possibility of being even more of a burden than they already consider themselves to be.

As Parkinson's progresses fatigue frequently sets in, it becomes harder and harder to engage in activities. Patients often recount how they can only schedule one thing in the day. They have to conserve energy. They are seen to do one thing, like going to a doctor’s appointment, and spend the rest of the day sitting in the living room and not really participating in much of anything else while they recharge. The appearance is apathetic. However, inside they are aware of needing to conserve energy and being frustrated that the illness only allows that one activity in the day. Other patients with Parkinson's can look very passive because they do not want to do something wrong and feel more of a burden. For instance, they may be aware that their balance is poor and their partner is very afraid of them falling. This results in lots of sitting and not engaging in other activities. They have the desire to be more active and are halted by their consideration of their partner and do not want to cause any problems.

In dealing with apathy there are a number of self-management strategies that may be of help for the person with Parkinson's. These include:

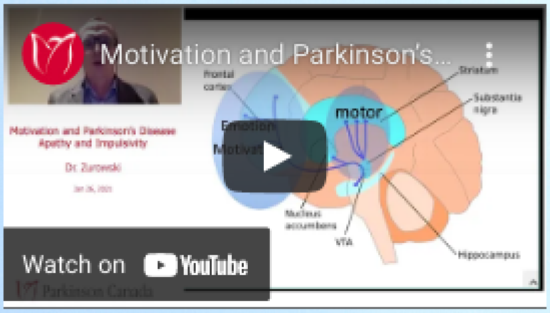
1. Break tasks into manageable chunks
2. Write down each positive thing experienced in the course of the day
3. Take credit for small accomplishments
4. Be kind and gentle with yourself
5. Be mindful of the moment
6. Attend helpful events
7. Buddy up for activities
8. Join groups
9. Ask for help

Partners can also be helpful by praising accomplishments, avoidance of being overly judgmental or critical, encouraging activities, doing tasks together and helping with the self-management strategies listed.

In some cases medications may be useful and needed. These are usually prescribed by physicians experienced in the treatment of patients with Parkinson's. Medications needed will depend on the suspected roots of apathy, although there may be significant overlap among the causes. Mainstays include dopamine agonists such as pramipexole, ropinirole, and rotigotine patch. There may also be a role for antidepressants, stimulants and cognition preserving agents. However, these medications have to be used judiciously as they can cause side-effects and the possibility of excessive activity such as seen with impulse control disorders.

Talk to your doctor about any mental health questions or concerns. We are here to help.

Mental wellness resources



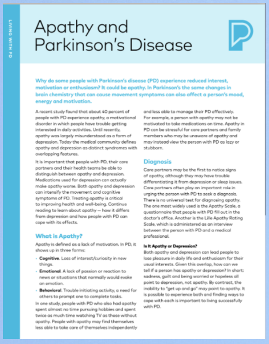
Motivation and Parkinson's...

Motivation and Parkinson's Disease
Apathy and Impulsivity

Dr. Zurowski

A loss of motivation, lack of interest and enthusiasm can impact the daily lives of those living with Parkinon's, as well as their family and loved ones. Trouble controlling impulses may also be a concern.

In this webinar with Parkinson Canada, Dr. Zurowski, Neuropsychiatrist at Toronto Western Hospital takes you through symptoms of apathy and impulsivity and shares his expertise on: What is this? Why does this happen? What can I do? and what are my treatment options? Watch the accompanying Q&A here.



Apathy and Parkinson's Disease

You may be experiencing apathy if you feel that it is increasingly harder to get up and participate in life's activities.

To better understand apathy take a look at the Parkinson's Foundation Fact sheet.

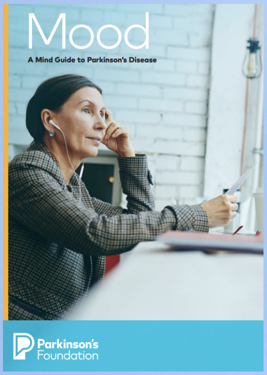
Parkinson's Foundation

Expert Briefings Webinars are put on by the Parkinson's Foundation, exploring symptoms, progression, treatments and management

On **Tuesday, April 20**, 2021 from 1:00pm - 2:00pm ET, Dr. Gregory Pontone, Director of the Parkinson's Neuropsychiatry Programs at Johns Hopkins will present Mental Well-being and Memory. This webinar will describe normal, age-related cognitive changes and strategies to stay well, and will review how cognition is affected by PD as it progresses over time.

You can register here. If you miss it and want to watch the recording or other Expert Briefings, check out their YouTube Channel.

Mental wellness resources continued

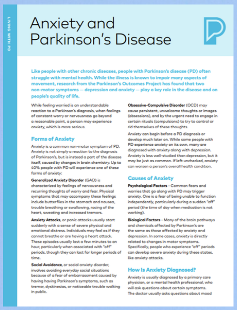

Mood
A Mind Guide to Parkinson's Disease
Parkinson's Foundation

This guide explains what mood changes can happen in Parkinson’s, why those affected might experience these changes and how to treat and cope with them.

Information, tips and stories will remind you that you are not alone on this journey.

Podcast: Managing Anxiety with Parkinson's.
As many as 40% of people with Parkinson's will experience some form of anxiety. Mental health professionals can help by providing effective talk and, when appropriate, drug therapies. Clinical psychologist Roseanne Dobkin, Professor of Psychiatry at Rutgers University, discusses the difference between reasonable worry and problematic anxiety.

Parkinson’s Foundation


Anxiety and Parkinson’s Disease

While feeling worried is an understandable reaction to a diagnosis, when feelings of constant worry or nervousness go beyond a reasonable point, this may be anxiety.

To better understand anxiety take a look at the Parkinson's Foundation Fact sheet here.

PARKINSON'S UK
CHANGE ATTITUDES. FIND A CURE. JOIN US.

Anxiety is one of Lorraine's main Parkinson's symptoms. She tells us about the impact it has on her life and physical symptoms as her condition progresses. Read her story here.

Not everyone with Parkinson's experiences mental health issues, but learning how other people deal with mental health challenges can help you to recognize what to look out for, can help you build healthy habits, and can help you to support others.

Click here for two thoughtful perspectives on mental health issues and strategies that work for them.

apda AMERICAN PARKINSON DISEASE ASSOCIATION
Strength in optimism. Hope in progress.

Mental wellness **support** resources

Ask for help if you need it.
If you find yourself struggling, don’t hesitate to reach out to a professional.

Some signs to look for:

- Less interest in thing you usually enjoy
- Withdrawing from things you usually do
- Trouble doing day-to-day life
- Struggling in domains that you previously weren't
- Feeling unmotivated
- Feeling like your emotions are out of control
- Trouble concentrating
- Changes in sleeping, eating, regular activity levels

There are many online resources available, help-lines and professional support:

- Contact your family physician
- Centre for Addiction and Mental Health (CAMH)
- Crisis Line: available 24/7
  1-866-996-0991
- Crisis Service Canada: available 24/7, 1-833-456-4566
  or text 45645 4pm-12am ET
- First Nations and Inuit Hope for Wellness: available 24/7
  1-855-242-3310, or live chat.
- Good 2 Talk: 1-866-925-5454
  or text GOOD2TALKON to 686868
- Togetherall:24/7 online support
- Wellness Together: accessible 24/7

Virtual *support communities*

Connect with people impacted by **movement disorders** over Zoom. Share tips, advice, experiences, ask questions and have a distanced social experience. Join here.

Mondays – Flying Solo. For single, divorced, living alone, or caring for someone else while taking care of yourself.
Tuesdays – Resilience Online!™ For EVERYONE!
Thursdays – Online Community for Care Partners and Adult Children. For care partners, adult children, and those with a loved one in a facility.

Online support groups offer comradery and comfort for those who cannot travel to meet in person, do not want to, or, given the current situation, in person may not be an option.
CurePSP offers the opportunity to interact with other **patients, caregivers, and family members affected by PSP, CBD, MSA, or related brain diseases.**
Check their website here.

Offerings include:

- **PSP/CBD** 101: An Educational Support Group for the newly diagnosed
- **MSA** 101: An Educational Support Group for the newly diagnosed
- People with **PSP**
- People with **MSA**
- People with **PSP/MSA/CBD** and their **carepartners**
- People with **CBD** and their **carepartners**
- **Carepartners** of people with **PSP/MSA/CBD**
- **Carepartners** of people with **PSP**
- **Carepartners** dealing with **advanced PSP**
- **Carepartners** of people with **MSA**
- **Grandchildren** of people with **PSP/CBD/MSA**
- **Adult children** of people with **PSP**
- After the loss: A **bereavement** support group for **carepartners**

To register - click the meeting link for the group that suits you. At the time of the meeting - click the meeting link for your group and follow the prompts.

You may contact the facilitator listed next to the meeting if you want more information. If you have questions about support services email: info@curepsp.org.

Acceptance

The uncertainty about COVID-19, the never-ending updates, and the changes that have been rapidly unfolding no doubt can make us feel on edge.

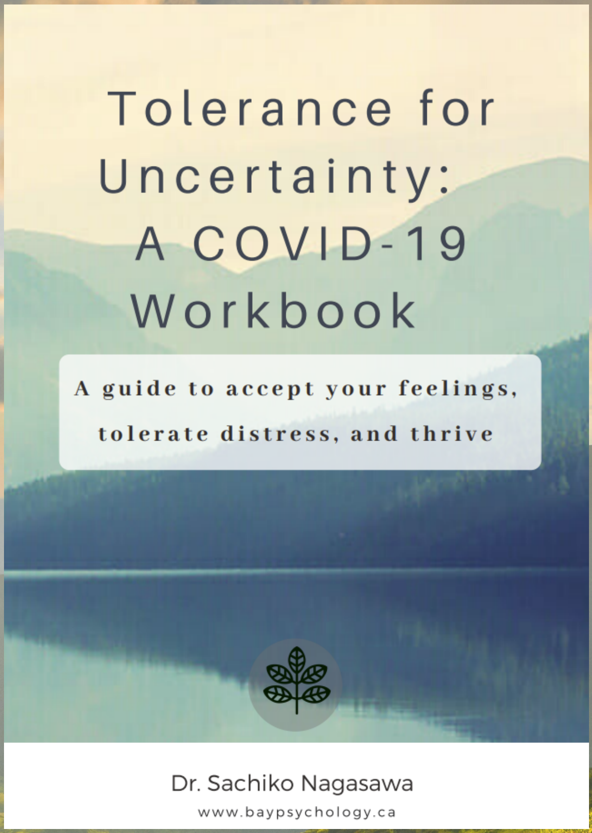
Radical acceptance is accepting the present without an intense desire to change it. When you stop fighting reality, stop resenting that reality is not the way you want it, and start *letting go* of bitterness. In essence, the idea is that *life can be worth living even with painful events in it.*

It is about recognizing and accepting the truth of the situation, even if it is difficult. It is also not burying our heads in the sand. For example, it is not continuing with our daily routine like nothing has changed - many of our typical routines have changed! It is about recognizing what is, and where we can act and respond accordingly. It is realizing what is out of our control, but also what is within our control.

Radical acceptance is hard, but taking an approach of radical acceptance can help when dealing with a situation that can be overwhelming - such as the current one.

Learn to accept your feelings, tolerate distress and move forward with grace despite not knowing what lies ahead.

Adapted from Tolerance for Uncertainty: A Covid-19 Workbook www.baypsychology.ca



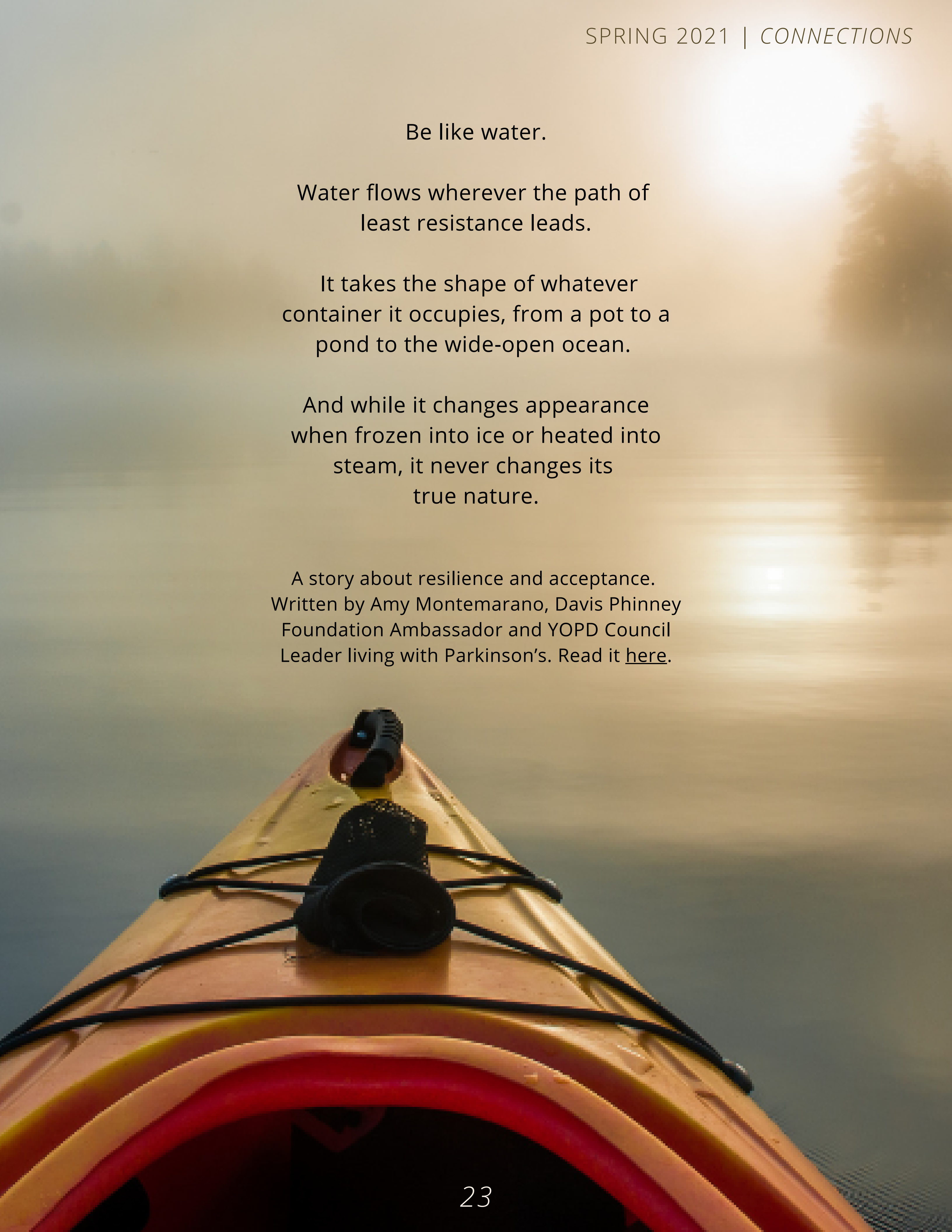
Tolerance for Uncertainty: A COVID-19 Workbook

A guide to accept your feelings, tolerate distress, and thrive

Dr. Sachiko Nagasawa

www.baypsychology.ca

> *"Stress is caused by being* here *and wanting to be* there."
>
> ~Eckhart Tolle



Be like water.

Water flows wherever the path of
least resistance leads.

It takes the shape of whatever
container it occupies, from a pot to a
pond to the wide-open ocean.

And while it changes appearance
when frozen into ice or heated into
steam, it never changes its
true nature.

A story about resilience and acceptance.
Written by Amy Montemarano, Davis Phinney
Foundation Ambassador and YOPD Council
Leader living with Parkinson’s. Read it here.

Self care reminders

Take some time to check-in with yourself. Reach inwards. Schedule quiet time to reflect and do a mental self-check. Determining if *you* are OK is not unlike what you would do if you were concerned about someone you love. What questions would you ask your friend or loved one if you were worried about them? Shift that mindset by asking yourself those questions.

Are you feeling drained, anxious, or overwhelmed? Think about what would help in managing those feelings. What will help you recharge?

Don't underestimate the power of distraction! If the news is fueling anxiety, step away for a little while. If it's hard to stay distracted, try dedicating a certain amount of time to one relaxing or healthy activity. It might sound silly, but you could even set a timer!

"Action is the antidote to despair."
~Joan Baez

Self Care Tips:

Find simple ways to stay active

Try something new

Find a routine

Find connection

Nourish your body

Be kind to yourself

Listen more to what your body and mind need from you

Practice gratitude

Practice mindfulness

Ask for help it you need it.

There is no shame in asking for support!

More tips on the next page!

Self care checklist

- ○ *Drink some water*
- ○ *Make a home cooked meal*
- ○ *Take a walk in nature*
- ○ *Dance party in your pj's*
- ○ *Light candles and sit in silence for a few minutes*
- ○ *Journal 5 things you are grateful for*
- ○ *Watch a sunset*
- ○ *Call a friend to catch up*
- ○ *Sit in the sun and take a few breaths*
- ○ *Write down an affirmation and put it on your mirror*
- ○ *Make a vision board*
- ○ *Plan out financial goals, it's never too late to start investing*
- ○ *Pop a bottle of champagne for no reason*
- ○ *Put on a great album and soak in the tub*
- ○ *Clean out your closet and donate anything that doesn't bring you joy*

Mindfulness

Mindfulness **is the practice of purposely bringing one's attention in the present moment without judgment.**

Try this *10 minute* guided meditation. Allow yourself to **slow down** and **become aware of the present moment.**

Take *10 minutes* for this guided meditation to help you **relax and relieve anxiety.**

MINDFULNESS WITHOUT BORDERS

Cultivate a mindfulness practice - listen to the recorded instruction, **notice your thoughts and accept things as they are**. Find one that works for you.

How the Movement Disorders care team has been coping

"Doing ‘30 day yoga challenges’ There are many online free courses that are excellent and usually only 30min / day!"

Dr. Susan Fox, Movement Disorders Neurologist

"Trying new recipes!"

Jana Huang, Research Coordinator

"My coping strategy has been comedy. The medicinal power of laughter is huge. I’ve binge watched Schitt's Creek, and it’s really lifted my spirits."

Dr. Naomi Visanji, Scientific Associate

"I’m looking forward to getting back into the swing of regular life, where I move a little more and snack a little less, whenever that happens."

Annonymous

"Learning to play the blues guitar with YouTube tutorials"

Julie Racioppa, Education Lead

Aside from discovering the Great British Baking Show and making my way through it. What I think has actually helped is developing new routines: I've found that developing new daily and weekly routines has been really helpful. A walk every morning clears my head for the day. Pizza-making on Fridays and movie night on Saturday are little things we can look forward to at the end of the week. Having little routines helps maintain structure and give rhythm to each week."

Dr. Emily Swinkin, Clinical Fellow, Movement Disorders

As a team we have kept close contact with our patients. Hearing from us and our concerns for them is greatly appreciated. Knowing they can call us and discuss how they are doing during these difficult times has helped us help them."

Patricia Williams Clinical Research/ Administrative Assistant

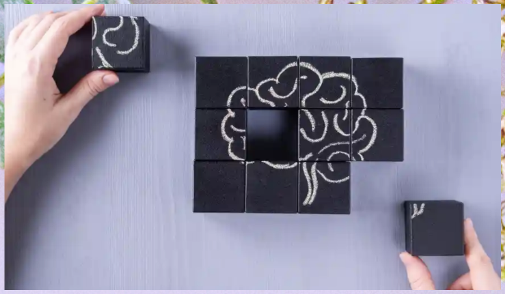
“"Like many people, I’ve become a connoisseur of elastic waistbands. My love language is pajamas."

Annonymous

At your leisure

Double click the images to take you to the articles

In a cherished friendship, we're mindful to be caring and wise, but we don't often afford ourselves the same caring attention.



Neuroscience shows we don't need to be physically close to have a profound effect on one another.

HuffPost unravels how COVID-19 has altered our mental health and how to manage as we move into year 2.

Sometimes self care is selfish and that's OK.

"What we practice grows stronger."
In this TEDx Talk, Shauna Shapiro presents the key ingredients for developing mindfulness - kind attention and practice.

Sit back and watch the Northern Lights at Kluane Lake, Yukon.

Patient Perspective

Old Friends

Written by Gordon Myers

It was a beautiful, sunny, summer day as I walked along Queen Street West, a neighbourhood I often frequented at night but not so often on a weekday afternoon. But here I was, standing in front of the Black Bull pub (a long time local on the corner of Queen and Soho), taking in the sun, when I heard an unmistakable sound. It was a loud, joyous, open mouthed scream (for lack of a better word). It was a sound I knew well.

My friend Aaron was about my age, a sort of ‘life of the party” kind of guy. More than anything he loved to leave his apartment on McCaul St. and make his way along the crowded Queen Street sidewalk to the Black Bull where, without a word spoken, a Rye and coke would appear at the bar as he made his way there to play chess with Sam the bartender. It was a simple expression of freedom for Aaron. “I’m going out today and ain’t nobody gonna stop me.”

That’s what I imagined Aaron saying to himself or to anyone who wanted to listen before heading out for the day. I say imagined because Aaron couldn’t speak. He could certainly communicate but, as with many people with Cerebral Palsy, he lacked the ability to control the muscles that create, and shape sounds for speech. He also couldn’t walk, had very limited use of his right hand and arm. In his wheelchair, he sat with his left arm lashed to the armrest to provide purchase so he could adjust his body position and use the middle finger on his right hand (the only one he could straighten) to point at words and symbols on a large, hard plastic word board. The word board was a great tool, but Aaron really preferred to communicate with sounds and corresponding eye movements and with facial expressions featuring a charismatic smile that could make your day.

I met Aaron in the late eighties at a group home in North York that was established specifically to house and assist disabled, young adults who were non-verbal. Most of the tenants were CP like Aaron but none were quite as physically disabled.

I worked there on a relief basis as an attendant assisting the male tenants with their personal care. It was good part time work that helped me get through some lean times and wasn't soul destroying like many part time jobs can be.

While the group home was a step up from his previous home it wasn't where Aaron intended to spend the rest of his life and was to him, an interim step on his way to truly independent living.

I worked at the group home less than part time, and only did that for a year or so, but in that time Aaron and I became good friends and promised we would stay in touch. But, as it does, life got in the way, and almost a decade passed before our chance meeting at the Black Bull.

He was in fine form. He looked great and was in his element. His goal of independence had been in many ways achieved. He lived in a modest, city owned, rent geared to income apartment that had 24-hour attendant care. He answered to nobody and but for the attendants coming and going had his home to himself. Aaron had a somewhat supportive family and had made many friends over the years and was for the most part a happy guy, but this was on his own terms. It was great to see and he was loving it.

We renewed our friendship and would meet from time to time at the Black Bull or at his place to watch sports. He had a few more really great years "Livin' the dream" on Queen Street before his health began to fail.

Immobility is a killer. They say on average it reduces your life expectancy by 25 years.

Aaron's health deteriorated over the next few years and with that went his independence. His needs were greater than the standard attendant care model could provide so he kind of languished, in and out of hospital, dependent on private care givers and friends. He had an amazing team of helpers (mostly women) who loved him and made the last year or two of his life worth living.

The last time I saw Aaron alive was in the palliative care unit at Mount Sinai.
I spent the night on his couch.

Aaron died on March 30th, 2010. I remember the exact date for a few reasons but mostly because a few days later on April 1st, 2010 I was diagnosed with Parkinson's disease. I can hear the neurologist's voice resonating in my subconscious, "you have Parkinson's disease."

I was in shock as I left the doc's office and made my way to the car. Aaron's death had been on my mind, but it wasn't until I was driving home that I thought of him and what he might have said had I been able to tell him about the diagnosis. I know he would have been supportive and genuinely caring but I also think he would have laughed. He would have laughed the laugh of a friend who truly understands. He would have been the perfect tonic to cure any hint of self-pity. So, as I was driving home that day a part of me was laughing with him.

Aaron's memorial was an appropriate tribute to a life pretty well lived. It was as he would have had it. I spoke along with a number of friends and family and shared a couple of stories and amusing anecdotes and had the sense to not mention my Parkinson's diagnosis. It would have made Aaron's eyes roll. In an understanding way of course.

And so, life goes on. My perspective on it forever altered but not dimmed.

I have siblings who are incredibly supportive and lots of friends who check in regularly to see how I'm doing and remind me to "skate" and "get open" and "don't give up the puck so easily" (Yes, I still play hockey).

My beautiful wife is incredibly supportive and always ready to assign chores lest the apathy that often comes with Parkinson's takes hold.

My life in music is as it started, a listener rather than a player, but, as I'm all too often reminded, "The business ain't what it used to be pal."

I keep myself busy with the usual day to day activities that come with owning property and living in a house. My dog and I explore the ravines of Toronto trying to find the ultimate off leash experience. For exercise, along with the dog walks, I'm a regular at a gym where, once a week, I do a high intensity, resistance (weights or machines) program to battle the loss of muscle strength that comes with aging and especially with Parkinson's disease.

I don't move as well or as quickly as I used to and words don't flow as fluently but I'm more fit than I have ever been and, thankfully, no more or less cognitively impaired than I was pre diagnosis. Life is okay.

I think of Aaron regularly, especially when those seeds of self-doubt start to rise to the surface.

In many ways we couldn't have been more different. Our tastes in music for instance.

He loved heavy metal, I love jazz and just about any music other than heavy metal. Of course I'm a Leaf's fan. Aaron was Habs all the way. He loved Crown Royal and coke. A beer or glass of wine suits me just fine.

The list goes on but where we both agreed, and thinking back perhaps why we became friends, was how we valued our independence. Aaron's dream was to live independently in his own space with the freedom and ability to come and go as he pleased. He was dealt a miserable hand at birth but never took his eye off of his goal. I, like most able-bodied people, for most of my life have taken my independence for granted and it wasn't until my Parkinson's diagnosis in 2010 that the thought of losing it became real.

With natural aging every decade offers fewer options but with neurodegenerative diseases in play those decades can become years depending on the pace of the disease's progression. Just about every health initiative I've ventured upon in the last 10 years has been a conscious attempt to move the odds of a long and fully independent life in my favour.

From food for the brain to resistance training for strength and balance. From talk therapy for a healthy mind to physiotherapy for a healthy body. From joining webinars to learn more about PD to volunteering for the MDC Patient Advisory Board to help move us closer to a cure or at least move us closer to the discovery and development of more effective treatments for all movement disorders.

Lofty goals? Hey, a guy can dream. As Aaron would say, well, you'll have to imagine it but, oh how I miss that sound. R.I.P. my friend.

By Gordon Myers

Dedicated to Aaron Shelbourne
August 8, 1959 – March 30, 2010

Aaron Shelbourne - CP. Friend, ally, life of the party. Lived life on his own terms.

Research Round Up

Our research program is actively working to advance new therapies and biomarkers, to develop new ways to treat and deliver better care.

→ We have several clinical trials and research studies that are actively looking for participants with a diagnosis of *Parkinson's* and are *not* taking any medications for it. Contact us for details!

→ Our *Cannabis* study is in full swing. If you have Parkinson's, are experiencing bothersome pain, are not currently using Cannabis, and are interested in hearing more we'd love to hear from you!

→ Parkinson's patients needed for a study investigating brain functions using TMS (transcranial magnetic stimulation).

→ Looking for Musician’s Dystonia patients for a study looking at brain connections using MRI (magnetic resonance imaging) and TMS.

Get in touch with us!

If you fit any of the criteria or are interested in other opportunities please contact **mdcclinicaltrials@uhn.ca** and a member of our research team will be in touch with you.

We have lots going on! For a list of research studies click here.

You can help move research forward.

There is a lot of advice out there about the best ways to take care of your health.

Embrace your wellness journey and try not to compare yourself to what others are doing.

At the end of the day only you know what works best for you.

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