

FALL ISSUE 2021

MDC CONNECTIONS

Functional Neurological Disorders

Masterclass with an invisible illness p.7

Don't you want to know? p.14

What's inside:

- 3** Connections
- 5** Tech Help
- 6** Move that BODY!
- 10** Ask our Neuro PT
- 11** Ask our Mental Health RN
- 14** Patient Perspective
- 18** App Alert
- 20** Care Partner Corner
- 22** Alternative Therapies
- 25** Arts & Artists
- 28** At Your Leisure
- 30** MDC Research Program

**Mind-body
connection: hear
from our experts!**
p.10, 11 & 12

Music therapy p.22

**Stimulating Brain
Discussions –
upcoming DBS
events! p.32**

**COVID-19 and
telemedicine p.33**

Welcome

Welcome to the *fourth* edition of *MDC Connections* — a publication 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.

Editorial Notes

EDITOR

Julie Racioppa

AUTHORS

Alix Goulet
Haseel Bhatt, PT
Keschey Marcelle, RN
Julian Kocjan
Julie Racioppa
Lindsay Ellis
Lindsey MacGillivray, MD PhD
Linda Redford
Peter Gilli
Sarah Lidstone, MD, PhD

CONTRIBUTORS

Gordon Myers
Linda Redford

COPY EDITOR

Melinda Davis

CREATIVE

Julie Racioppa

Please note that the listings in this publication 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.

MDC Connections is a collaborative effort by the Movement Disorders Clinic staff, the Integrated Movement Disorders Program, the Patient Advisory Board, and patient contributors.

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Connections

Welcome back readers!

I hope you are enjoying the beginnings of Autumn - a perfect time for crisp walks, warm drinks, and cozy sweaters. The seasonal shift reminds us that change is a natural part of life. By embracing the cyclical shifts around us - the temperature, daylight, the changing leaves - we become more skilled at recognizing our own innate capacity for resilience and adaptation.

In this Fall issue we focus on the importance of the mind and body interaction, how they are intertwined and influence each other. This perspective identifies ways to notice what is going on in your body and how your mind can influence your physical and mental response.

Family and friends may notice a tremor or quiet speech but they may not see other underlying symptoms. By definition, Movement Disorders include *visible* symptoms of mobility changes. However, there are many other symptoms that require attention and treatment even though they are less visible that people may not realize are linked to their diagnosed condition.

In this issue an article by Lindsay Ellis, writer and comedian, describes a masterclass on how to navigate life with an *invisible illness*. Lindsay describes 10 steps that you can take to maintain personal control over your quality of life. The first step is to listen to your body. Our bodies let us know when something is off, we need to listen. We can advocate for our self and remain a productive member of society. We need to understand our personal power and trust the process - life comes in seasons.

In this issue's *Ask our Neuro PT* section, Haseel Bhatt explores the connection between stress and symptoms. In a brand new column *Ask our Mental Health Nurse*, Keschey Marcelle provides strategies to help you tune in and maximize the benefits of being aware of your thoughts. You can listen to an excerpt from a patient describing how breathing exercises were pivotal in connecting the mind with parts of the body on page 11.

This issue is all about that connection. You can also read how Dr. Sarah Lidstone, Neurologist and Dr. Lindsey MacGillivray, Psychiatrist thoughtfully and expertly view this interaction (page 12).

Our feature articles are written by people with Functional Neurological Disorder - surprisingly common, yet hard to understand. They are caused by a *problem* with how the nervous system is *functioning*. We think that ALL movement disorders can benefit from learning about the mind-body loop, and the importance of mindful movement.

Our Summer issue on care partners generated so much positive feedback that we are proud to announce a brand new section *Care Partner Corner!* Each issue will feature an article or resources devoted to carers. This issue features a heartfelt article by Alix Goulet - a devoted care partner and wife.

Continuing our new section on *Arts & Artists*, this issue features Julian Kocjan - check out his Fall photographs and marvel at that squirrel on page 27!

Join us in savoring the seasonal change by noticing the small things, like the colour of the sky or the delightful sound of crunchy leaves. Visit the farmers market - cooking with the seasons lends itself deliciously well to mindful eating and provides an opportunity to connect to the natural world. Variety is the (pumpkin pie) spice of life. We don't have to love everything about the change of seasons, but savoring it all - even the parts that may feel less appealing to us - can lead to new ways of understanding our experience. Savor the equanimity, take the good and the bad - whichever is emerging right now.

We hope you enjoy our Fall issue of *MDC Connections*.

Take care,

Julie Racioppa, Editor

Linda Redford, Patient Advocate, Advisor and Care Partner.



Apple crisp - a personal favourite, homemade by my father :) [Betty Crocker recipe here!](#)



Have a favourite recipe? Share yours at movementdisorders@uhn.ca
We'll include it in next months issue!

Tech Help

This section highlights technology tips, tricks, software and programs. Aimed to empower you to be comfortable with technology and equipped with the tools to do so!

Suggestions are welcome - feel free to email movementdisorders@uhn.ca



SteadyMouse

Recommended by Bob Sherman - a person with Parkinson's tremor.

"SteadyMouse is always turned on on my PC, and it is invaluable for me; I would almost say essential. My tremor when mousing is still a big pain much of the time, but what SteadyMouse does is keep the mouse clicks from making unwanted things happen - e.g., activating links I don't want to open, closing or switching between tabs, moving around a document when I don't want to, etc. In fact, once or twice

I've disabled SteadyMouse by accident - you enable and disable it by pressing the NumLock key - and it was hell until I realized I'd disabled it."

From their website: SteadyMouse assistive software detects and removes the shaking motion before it reaches your cursor, and blocks accidental clicks. The entire mouse experience goes from a chaotic battle to an enjoyable reality.

UHN MDC is not familiar with the product, but passing on a recommendation.



Toronto Public Library Seniors Tech Help is a one-on-one service that can help you connect with family and friends online, borrow e-books, audiobooks, newspapers and magazines, shop safely online, and access health and support services.

Call or email to talk to staff right away or to set up an appointment.
Telephone: 416-393-6225 Email: techhelp@tpl.ca

➡ *Check out a complete list of classes and events for older adults.*



Virtual Visit help guides

UHN has important tips for preparing for a virtual visit [here](#) and [here](#).

The **Movement Disorders Clinic** has a quick guide [here](#) and more details [here](#).

Move that BODY!

The following activity guide is designed to inspire you to move more and get out of your comfort zone . Try something new!

Start
slow

Listen to
your body

LOW INTENSITY

MEDIUM

HIGH

Aerobic



2 times per week

LEISURE WALKS

LOW IMPACT
CARDIO

DANCE
PARKINSON'S

Strength Training



2-3 times per week

VOCAL
EXERCISES

10-MINUTE
FULL BODY
WORKOUT

20 MINUTE
FULL BODY
WORKOUT

Balance Training



2-3 times per week

10 BALANCE
EXERCISES

STANDING
YOGA

20 MINUTE
YOGA FLOW

Flexibility



2-3 times per week

10 SEATED
STRETCHES

15 MINUTE
DAILY STRETCH

15 MINUTE
FULL BODY
STRETCH

Masterclass with an invisible illness

10 Lessons For Navigating Life With An Invisible Illness

By Lindsay Ellis

**This is a humour/satire piece*

Welcome to my masterclass on how to navigate life with an invisible illness. This class is also open to you even if you are temporarily sick or visibly ill.

Now I must warn you, this class is a major commitment. It is all day, every day. Not only that, but this class takes place everywhere you go.

Before I get into what we'll cover, I'm required to tell you that the costs of materials and supplies vary significantly. These costs range from every penny of disposable income to your entire life savings, including any inheritance. Now, if you would like to crowdfund that is entirely up to you. The question to ask yourself before you do is "Do I want the embarrassment of admitting to the world that I am sick, poor, and a complete drain on resources?" If the answer is yes, gofundme is a great public shaming platform.

I've designed this masterclass to be self-directed and self-paced. Some lessons you might get right away, some you'll have to revisit every so often, and some you'll have to repeat indefinitely. Do not get discouraged. You will master it all eventually.

Lesson 1: Listen to your body

When you first get sick, you'll know that something isn't right. At first, you'll dismiss it and push through not wanting to change your current lifestyle. Maybe you just ate

something that was off or you've been pushing yourself too hard. That's when the comments will flood in from loved ones, and sometimes even, coworkers. "You don't look good. Are you getting enough sleep? You don't seem like yourself." This will prompt you to begin to google your long list of symptoms which will lead to a long list of medical conditions, treatment plans, and specialists to investigate. You will be adding to this list throughout your life. Medical professionals will marvel at your ability to be in tune with your body, as you distinguish a new symptom from an inconvenience.

Lesson 2: Advocate for yourself

You will visit the doctor with your long list from listening to your body. The doctor may or may not give you a diagnosis, result, or prescription. I can assure you, it will be frustrating and you might want to give up and have someone else fight so you can get the care you need. Your relatives or doctors aren't great advocates for your needs. You'll learn that the only person who can be your advocate is you. Strategies to be your own advocate will include finding clinics that specialize in your symptoms, asking for referrals and off-label drug usage, and joining a Facebook group to learn what other people did. In order to truly grasp advocating for your health, you'll have to repeat this lesson indefinitely.

Lesson 3: Get it done now

One day, you'll have a good day. You'll wake up with energy. You won't have pain or fatigue. You'll be able to fully participate in activities you previously enjoyed. Now, I need to warn you, there is no guarantee as to how long this good day will last. Will it only be a good day until the afternoon? Will it be two good days, a week, a month? Before you jump in with both feet to do all the things, pick which activity you want to do cause there is no telling when another flare-up will knock you back down.

Lesson 4: You are a productive member of society

Inevitably you'll be in a situation where you're unable to work. Then you'll be faced with numerous encounters that begin with the reductive question: "So what do you do for work?" Here you are faced with a Sophie's Choice. You can either tell them the job that you can no longer do and no longer have, or you admit you are not part of the workforce. If you admit you don't work, you'll be faced with accusations of laziness or put into a box of society's losers, especially because you look just fine. You must learn to ignore these responses! Modern society might believe people are only as productive as their economic output but this is only because the truth got lost. You'll find the truth when you learn that just existing and having strong bonds with friends, family and community makes you a productive member of society.

Lesson 5: Who's got the power

A flare-up will cause you to be bedridden. You'll be left feeling powerless over your life and health and you'll want to embrace a victim mentality. Being a victim increases

the sympathy you get from other people. They'll be nicer to you and you'll feel special. However, some people will still accuse you of looking for attention and utter the phrase "Suck it up buttercup." Although, you won't "suck it up," you will learn that the only things you can control are your attitude and your effort. With this newfound power, you will no longer tolerate the victim role for yourself. You'll take responsibility for how you show up in the world when you have the energy to go into it.

Lesson 6: You are worthy

You will struggle with self-worth. Thoughts such as 'why do I deserve to live when others have died of this disease' to 'do I deserve the attention, love, and help from others when my body is broken?' will come up frequently. This is merely a test. The two most common misconceptions that the voice in your head tries to make you believe are that you are unworthy and unloveable. You will pass the test when you understand that being alive makes you worthy of being alive and being human makes you worthy of love.

Lesson 7: Trust the process

After listening to unsolicited advice from friends, family, and strangers on the internet, you'll be left feeling that your experience is wrong and, therefore, somehow you are wrong. Through a sequence of trial and error, you will discover that you are a human, having a human experience. You will ask yourself questions like: "Why am I not working out more? Why don't I eat better? Why can't I do whatever I want?" I would like to take this moment to reassure you that your life is unfolding exactly as it was meant to be and you are doing what you can with what you got.

Lesson 8: Life comes in seasons

Everyone knows that seasons don't last forever. Just because it's cold and snowing doesn't mean that it will never be hot and sunny again. Internalizing this knowledge, you'll stop believing that just because you're having a flare doesn't mean you'll never participate in life again. It is simply the wintertime of your life and summer is coming.

Lesson 9: Your heart is three sizes too big*

At this point in my masterclass, your sense of compassion and empathy will have increased. You'll realize that everyone is going through their own life struggles. People who are in pain, whether it's physical or emotional, act out. At this point, you are encouraged to offer yourself forgiveness for any time you snapped at or were frustrated with loved ones.

* Not literally, unless students also have cardiomegaly.

Lesson 10: Everyone will be in this class eventually

You will lose friends and family throughout this masterclass. Those people who disappear are the ones who don't realize that they are in fact a TAB — a temporarily able-bodied person. In time, everyone will be in some version of my masterclass. When you find your community, you will find a home and actually be grateful that the wrong people left your life and the right people came in.

Congratulations, this masterclass is the first step in finding that community.



Lindsay Ellis (she/her) is a Canadian writer and comedian who has a chronic, invisible illness. Currently, she is developing an online course entitled: More Joy Life, to empower people to maximize joy in their everyday lives. She is a writer with The Beaverton, Canada's largest news satire site.

Lindsay can be found on all social platforms as @mslindsayellis and online at lindsayellis.com

Ask our Neuro PT

By Haseel Bhatt, PT

Haseel answers your questions about exercise, physiotherapy, motivation and more!

Q: I've noticed my symptoms are worse when I'm under pressure at work. Is there a connection between stress and symptoms?

HB: We know that stress and anxiety can often make symptoms worse in the moment. For example, it is not uncommon that symptoms such as pain, tremor and dystonia worsen under stressful conditions due to the body activating the 'fight or flight' response. These symptoms have been traditionally targeted through medication which can be extremely helpful. We are now learning that physiotherapy strategies can also be effective. Strategies such as stretching, body-based exercises and muscle relaxation techniques can help trigger the body's parasympathetic response to help regulate the nervous system and better manage these episodes of symptom exacerbation.



Haseel Bhatt, neurological Physiotherapist

Learn more!

What is the *sympathetic nervous system*? This branch of the nervous system is responsible for the body's ***fight or flight*** reaction when we respond to a perceived harmful event, attack or threat to survival.

What is the *parasympathetic nervous system*? This branch of the nervous system is responsible for the the body's ***rest and digest*** response when we are relaxed, resting, or digesting.

Podcast alert!

Physical therapists with a neurological specialization create custom plans to help people with PD who have balance issues.

Listen to Podcast Episode 90: Movement Strategies: Mobility, Falls & Freezing of Gait to find out how addressing movement issues can also improve mental state.



Ask our Mental Health Nurse

By Keschey Marcelle, RN

We are delighted to introduce our mental health nurse Keschey Marcelle, an expert on all things to do with mood and mindfulness, with many effective strategies and insights up her sleeve!

Q: Is stress harmful?

KM: Stress is a regular part of our daily life, and our minds and bodies are prepared for small doses of stress. Long-term, prolonged stress can increase our risk for mental and physical problems. Harmful effects of stress show in thinking, feeling, behaving or the body. Trouble concentrating on thoughts, difficulty with decision making, moodiness, emotions, headache, fatigue, and social withdrawal are all symptoms that can be stress-related and an indication of mental health problems.

Q: What can I do to stress less?

KM: Lindsay Ellis has it as lesson #1 in her master class **"listen to your body."** Our body lets us know when there is something off, we need to listen.

Self-care is important and is not being selfish or unproductive. Strategies include finding ways to slice out more "me time" for yourself, improve the quality of your sleep, increase your physical activity and connect with people for support. Targeting the harmful effect of stress on your mental health helps with overall health and wellbeing.



Keschey Marcelle, mental health Nurse

Q: I've heard a lot about the importance of the breath, do breathing exercises work?

HB & KM: [Listen](#) to a snippet of a patient that has completed our program and how breathing exercises were fundamental in her Functional Movement Disorder (FMD) recovery.

Thank you Keschey and Haseel!



[CLICK HERE](#)
To LISTEN

The Mind & Body Link

**Q & A with Dr. Sarah Lidstone,
Neurologist and Director of the
Integrated Movement Disorders
Program (IMDP) and Dr. Lindsey
MacGillivray, Psychiatrist and
Clinical Lead IMPD**

Interviewed by Julie Racioppa

1) What is your view on the interconnectedness of the mind and body?

SL: Our mind, brain and body are connected and influence each other. For example, emotions influence movement, and thoughts influence emotions, which influence movement. Body language is a direct example of how emotions are manifested in movement and that occurs subconsciously - there aren't conscious thoughts attached to somebody generating body language, but there's a direct highway between emotions and what the body is doing. These connections are on a spectrum of being positive things experienced by the person, but also negative things. An example of positive things - when somebody feels good or joy, they move faster, think quicker, they're more productive and accomplish more, they're moving through life in a very different way than, for example, when someone is experiencing depression or anxiety. At those times the body is doing something very different. In the case of Parkinson's, their tremor is worse, their dyskinesia is coming out, they have more freezing of gait - their whole ambulation mechanism is impaired - and this is all related to how anxious they are in any given moment. The link is always there, but it's taking different shapes depending on what the emotional state is of that individual at that time.

The link is always there, but it's taking different shapes depending on what is the emotional state of that individual at that time.



Dr. MacGillivray and Dr. Lidstone all smiles on a bright Fall day

LM: Agreed! It's important to remember that the division between mind and body is an artificial one. In reality, the functioning of our brain and body is intimately connected to how we think and feel. For example, when we are worried or anticipating that something bad might happen, many of us experience tension and fatigue in the body. Tremor might be worsened. Conversely, when we feel relaxed, hopeful, or joyous, bodily tension dissipates, and we may be able to move with more ease.

These mind-body connections also work in reverse - i.e., the state of our body can change how we think or feel at any given time. When our body is tense or when our nervous system is working in overdrive, we are more likely to feel worried, irritated and on edge. Experiencing abnormal movement might trigger anxious thoughts. The good news is that understanding these mind-body relationships gives us the power to modify them - we can influence how the body functions by changing how we think and feel, and vice versa.

2) *What strategies or tools do you suggest to balance the mind and the body?*

SL: The first step builds on what the rest of the team members (Keschey and Haseel) said in the articles *Ask our Neuro PT* and *Ask our Mental Health Nurse* and that is cultivating an awareness of where IS the mind in any given time and where is the body at any given time. Developing this as a daily practice is important, like meditation. People often separate 'oh you have to see this therapist to treat this mental health symptom', so you're going and you're having your anxiety or your depression treated. Then you have to go to the gym and do exercise to treat the body. Mind-body exercises are ways that you can do both at once, simultaneously targeting the emotional state and the body. Yoga is an example of this – incorporating breathing, movement and quieting the mind helps to regulate the nervous system. Things like dance - where there is music and other people, also target multiple parts of the brain and body. Any type of activity that combines movement with socialization, like walking with friends or family, or doing exercise classes together benefits the brain in multiple ways.

Missy's story is a perfect example. Missy is a wildlife photographer and a person with Parkinson's. She hated going to the gym and using the treadmill, but when she goes out walking in the woods, taking photographs of birds, it replenishes her in a totally different way. She's exercising on her own terms, in her element.

The good news is that understanding these mind-body relationships gives us the power to modify them - we can influence how the body functions by changing how we think and feel, and vice versa.

Start to consciously pay attention to your thought patterns, your feelings, and the state of your body. Noticing that your shoulders are raised and tense? This could be a signal that you are feeling stressed or frustrated.

LM: From my perspective, learning to read your own mind and body's signals can be helpful. Start to consciously pay attention to your thought patterns, your feelings, and the state of your body. Noticing that your shoulders are raised and tense? This could be a signal that you are feeling stressed or frustrated. If you notice yourself feeling on edge, this might be a cue that there are a lot of things going on around you and that you're feeling overwhelmed. Intervening in these moments with a simple breathing exercise or muscle relaxation technique can dramatically change how the nervous system is functioning, and through feedback circuits to your brain, can change how you feel. Similarly, holding up a "stop sign" to your thoughts when they start to go too quickly or take on a catastrophic tone can help prevent those worries from taking control, and may help your body be less tense and tremulous.

3) *Can you touch on other movement disorders? Does this apply to a variety of movement disorders?*

SL: Absolutely. It applies to all of movement, whether it's a disorder or not. We know dystonia is worse when people are stressed, we know tremor is worse, functional movement disorders are very tied to what someone is experiencing in their environment, good days and bad days. I would say this applies to all of movement and probably actually all of medicine, not just movement. Any chronic illness where people are experiencing bodily symptoms are going to be impacted by the state of mind at that given time.

Thank you for your insights Dr. Lidstone and Dr. MacGillivray. We've learned a lot!

Patient Perspective

Don't you want to know?

By Peter Gilli

At some point during the long night of my wife's 25th birthday party, I felt a piercing pain in my throat and discovered I could no longer speak. We had been celebrating with friends at a bar in Providence, Rhode Island, raising our voices and shouting to be heard over the packed crowd. I thought little of the pain when it started - I was tired, it had been a long week, and it was loud in the bar. So what if my voice was sore? I borrowed a notepad from the bartender and jotted a note to our party: I was going home to rest. No big deal.

Unbeknownst to me, what started as a minor, transient injury to my vocal cords triggered an avalanche of changes in my brain. The neural cascade began quietly, and by the time I understood how much trouble I was in it was too late to get out of the way. My newly broken voice refused to fully recover. And within a year, whatever it was had spread: my hands lost their grip strength. I started to feel disconnected from my limbs. Then I lost my ability to walk.

It took a long time to understand what happened. Eventually, I was diagnosed by a neurologist who finally gave the thing a name: it was Functional Neurological Disorder.

Functional Neurological Disorder, or FND, is a condition that has long evaded medical understanding. It's a biological brain disorder, as disabling as Epilepsy or MS, and one of the most common neurological disorders worldwide. Despite that, most doctors don't learn about it during medical school, and researchers are only now unraveling its biology. As a result, FND goes undiagnosed in the hospital and unspoken in our culture.

"Unbeknownst to me, what started as a minor, transient injury to my vocal cords triggered an avalanche of changes in my brain."

What is Functional Neurological Disorder (FND)?

FND is a problem with the functioning of the nervous system and how the brain and body send and receive signals. Different people with FND experience different levels of severity of symptoms. FND is usually treatable with a rehabilitation approach to "re learn" normal function.
www.fndhope.org/fnd-guide/

How did it come to this? A cursory glance at the history of FND - and its dolorous litany of medical failures - provides an answer. In the 19th century, FND was known as Hysteria (a term which, among the public, eventually came to mean "blowing things out of proportion"). Later, it was called Conversion Disorder, reflecting the assumption that patients were "converting" suppressed emotional traumas into physical disability.

This created a culture of disbelief among physicians, many of whom doubted that the symptoms of FND could possibly be real. Others described it as "all in your head" - ironically meaning "not a true brain disorder at all."

And yet, it certainly is. Brain scans, clinical exams, and the stories of people with FND leave little doubt about that.

Here's what we know:

In FND, the brain is often jolted out of its normal patterns of function - patterns that govern how you move your body, interpret sensations, and experience your life.

The jolt may be triggered by "adverse events", which can be a physical injury like a hiking accident, or an emotional trauma like spousal abuse. Other brain disorders can also be a trigger: one study found that $\frac{1}{3}$ of people with Parkinson's also developed FND. For many people, multiple causes converge to disrupt common pathways in the nervous system.

Whatever the trigger, these traumas can change the brain in profound ways. For starters, evidence suggests that they might push the brain into a kind of over-learning mode, in which it absorbs the details of disaster too vividly. From then on, it adopts the sensations and movements it learned during the crisis as a new default. *That* becomes its new set of rules for managing the body. You break your arm, the arm heals, but it never answers to you again. The brain re-creates the break, forever.

I can't tell you what would have happened had I known this when I first got FND. All I can tell you is what did: I became mysteriously disabled, I felt like an alien in every room I entered, and I didn't even have a name for what was happening to me. I found out that society, despite tropes of "inspirational" disability, is not kind to the disabled.

At Pearson airport, attendants wheeled me halfway through a terminal, became distracted by some more pressing matter, and left me there, stranded. At social gatherings, people I didn't know grabbed my cane and did vaudevillian dance routines with it. Others asked if I really needed my mobility aids, or if they were "for the look."

And yet, hospitals were always the worst. Neurologists put me into MRI after MRI, and after finding nothing, told me that there was little they could do. They said things like, "We don't have a specialty for you." Or even, "You don't have genuine weakness." I asked, "Then why can't I get out of this chair?"

No one had an answer, but that didn't seem to bother them. They simply referred me elsewhere, relieving them of the problem of having to help me.

What did they miss? One of the first things every aspiring medical student learns.

In medicine, the question of what ails a person is often resolved by looking at their anatomy: a fracture on an X-Ray confirms a suspected broken arm. Certain lesions in the nervous system show that a person has MS. But these tests aren't useful for FND because they leave out what the brain actually does;

its physiology - the brain functions that keep us alive. Function-oriented neurological exams show that in people with FND, core systems in the brain which handle attention, body regulation, emotion, and

movement control have become dysfunctional. There isn't a problem of structure here; there's no collection of plaques like in Alzheimers, or lesions like in hemispatial neglect. Instead, the brain has locked itself in a loop it can't get out of.

After several years of living with the spasms and disorientation of FND, I was beaten down and heartily sick of the loop. So I sought out treatment from experts: first with Dr. David Perez at Massachusetts General Hospital, and later with Dr. Sarah Lidstone at Toronto Western Hospital. My recovery came a bit at a time, and hasn't been linear.

But there are indeed treatments for FND, and they worked for me: physiotherapy to retrain my movements, occupational therapy to help pace myself through the day. There were pain control techniques and anxiety therapies to help calm the brain's defense circuits and free up normal movement patterns. No one thing "fixed" my FND.

But together, all of it helped.

"My recovery came a bit at a time, and hasn't been linear."

I have returned to full-time work, and am slowly resuming things I once loved to do. Last week, I rode my bike for the first time in a decade.

The story of FND, until very recently, was a story of millions of people in legitimate suffering who were treated as if they were not. But there is a flip side to everything: because so little has been understood about FND, and so little effort expended in pursuing it, there is now a tremendous amount to gain. And there is good reason to believe that these benefits will ripple out to people with many other health conditions.

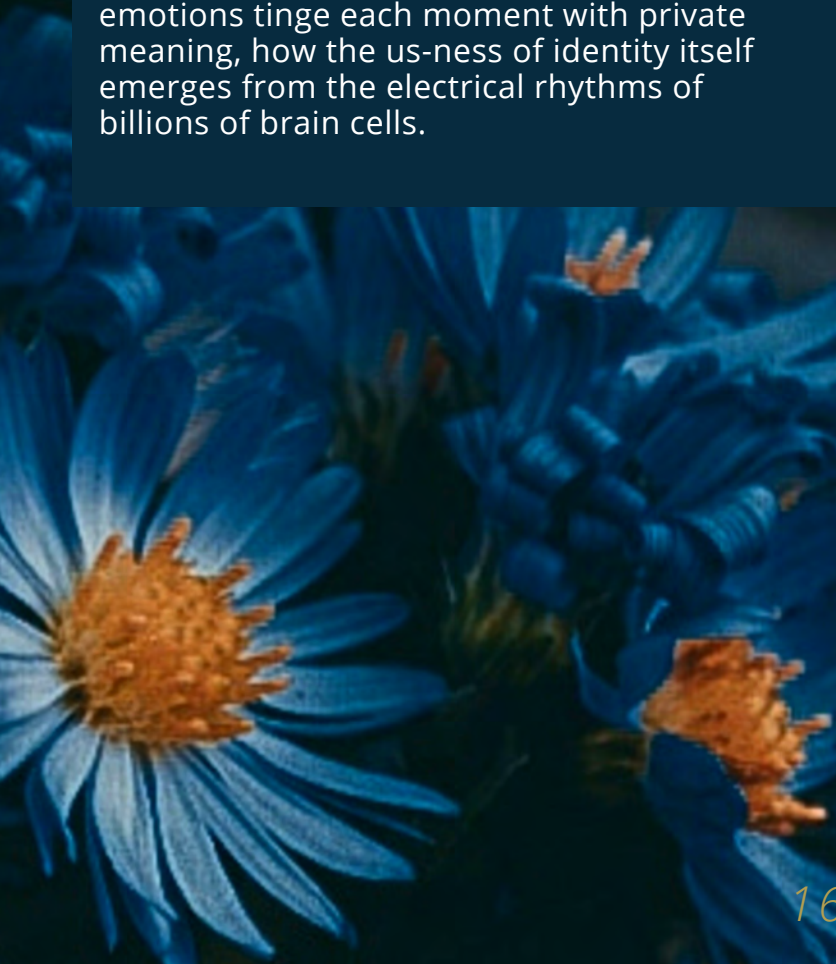
People with FND are your friends, your neighbours, your family. You may have it yourself. How strange, then, that we have been treated as "other", as separate and different somehow from the rest of humanity, when the brain networks that produce FND also produce all our human experiences: how we feel in our bodies, how we think and see and remember, how our emotions tinge each moment with private meaning, how the us-ness of identity itself emerges from the electrical rhythms of billions of brain cells.

"The story of FND, until very recently, was a story of millions of people in legitimate suffering who were treated as if they were not."

What might happen if society saw people with FND as we are - people much like you, who are experiencing suffering that could happen to anyone? What lessons could FND show us about how to aid people whose brains have been ravaged by disease? What if we rejected the "hysterical" stereotypes and instead approached our inner mind-body loop with curiosity, knowing that nature invested millions of years in its design? What if, by doing so, we could better understand this

embodiment machine, this thing that makes us us - an organism like any other, but one that reflects upon itself, that moves with unique awareness, that remembers and believes, that can dream and paint and yell bad karaoke and love the touch of each other and the warmth of the sun?

Don't you want to know?



Peter in a 2019 concert performance

Functional Neurological Disorder Resources



Neurosymptoms.org - A Patient's Guide to FND

A comprehensive resource to learn about Functional Neurological Disorders (FND), causes, symptoms, treatments, and personal stories. Check out this short [video "What is FND?"](#)



NORD - National Organization for Rare Diseases

Read about signs and symptoms, causes and treatments for [FND](#).



FND Hope

Learn about FND with webinars, videos, resources, and peer support. Their [YouTube channel](#) is a great resource!



FND Recovery

A personal blog about getting an FND diagnosis, the tools to recovery and pursuing peace.

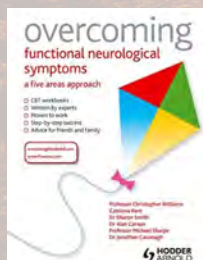


FND Portal

A personal blog and a place for research and article links, written and compiled by an FND patient and advocate.

Check out [All Reflections are Light](#), a video recording shown at the World FND Month conference, organized by [FND Hope](#).

[Follow FND Portal on Twitter](#) for insightful musings, information and perspective backed by evidence-based research.



Overcoming Functional Neurological Symptoms

This book uses Cognitive Behaviour Therapy (CBT) to help people experiencing a range of medically unexplained symptoms, including chronic headaches, fatigue, dizziness, loss of sensation, weakness and numbness.

App Alert!

Apps are a great way to try out something new and connect with others. Each issue we provide suggestions for apps vetted by our team that we think provide value. Try one out! Or try them all!

For
Functional
Neurological
Disorder



myFND

An app designed to help you with your symptoms of FND. Learn about FND, understand your symptoms and how to manage them, step back and find patterns, and find links to support resources.

For chronic
pain



Curable Pain Relief

Your pain experience and your recovery program are unique. Curable can help you overcome fear of movement, reduce health anxiety, relax the nervous system, and navigate flare-ups.

Medication
reminders
and more!



My Therapy

Medication tracker and pill reminder. Also includes a mood tracker and a health journal that you can print and share with your doctor.

For your
wellbeing



Headspace

Learn the life-changing skills of meditation and mindfulness in a few minutes a day with Headspace. Choose from hundreds of guided meditations that can help you stress less, reduce anxiety, and get restful sleep.

Mind and body wellness

Where are you carrying tension?

When you're feeling tense or anxious, where do you feel it most in your body? Some people feel a tightness in the chest, or find that their jaw or forehead is locked or clenched.

Simply noticing where the tightness is can help start to release it.

Bring your attention into those physically tense areas—even when it's uncomfortable. Letting yourself be curious about what's going on helps to disrupt the cycle, or the "anxiety habit loop".

The goal is to be able to quickly take note when you're holding tension in your body, tune in to those sensations, and let them go.

Take a deep breath.

What's your stress index?

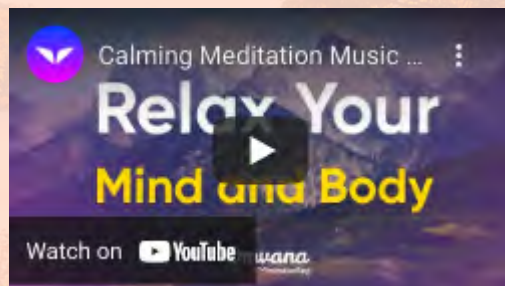
Filling out this quick questionnaire by the Canadian Mental Health Association can help you recognize when you are stressed.



3 ways to find a little softness

- 1) Try this quick body scan to tune in to your body and anchor yourself to where you are right now.
- 2) Explore this practice to reimagine and shift your relationship to stressful moments—rather than trying to hold them at bay.
- 3) Use these techniques to release tension in your eyes, face, and head

Adapted from Mindful.org.



Enjoy 35 minutes of calming meditation music to relax your body and mind.



Ten Years In – *What I Wish I'd Known*

By Alix Goulet

What is the most significant thing about being a Parkinson's disease (PD) care partner that you know now but didn't see coming ten years ago? How would your PD partner answer the same question?

As a PD care partner, it's difficult to answer this question. Quite frankly, back when my husband was diagnosed, I didn't know anything about Parkinson's, I didn't know what was going to happen to my husband, or us, or anything. I didn't see anything coming because I was stunned.

This journey (as they call it) with my husband, has been one of continual, and sometimes awfully fatiguing, learning. But to your pointed question: what do I know now that I didn't see coming ten years ago.

1. I now know that Parkinson's is a condition that affects the mind and the mood of the PD partner, just as much as the physical condition. In my view, in retrospect, I see very clearly that the first manifestations of Parkinson's in my husband was a kind of depressive fog that slowly moved in on him, taking away his spark, lowering his spirit, dampening his enthusiasms. My husband's affect flattened in a way I was not expecting. In fact, and I want to write about this in more length sometime, when we got hit with his Parkinson's, I thought my marriage was failing. In a way, getting the diagnosis was a kind of relief of a certain kind, a kind of "a-ha" moment, of understanding that there was something going on, that was bigger than us, but now has become our new life.

2. Speaking of the flattened affect, I now know about the Parkinson's mask. I realize in the grand scheme of all the physical, mental, and cognitive challenges faced by people with Parkinson's, a certain rigidity of the upper lip or the face may not be high on the priority list of concerns. But, as a PD partner, again, this was originally devastating. My handsome, lively, sparkly eyed husband, always quick with a light-hearted quip or an admiring glance, has become someone with a flat, drawn out face, slower to smile. The hundreds, the thousands of lightening quick expressions that whip across a person's face in a given day just kind of disappeared. It was like a language we spoke, of look and touch, faded away. ***I miss my husband's sparkly face. I hate that Parkinson's takes that away.***

3. I also know now that there are about as many ways to experience Parkinson's as there are people with PD. The course of PD is not straight. No two people have the same trajectory. There are people we met in the first, early years, at the Parkinson's support groups, back when my husband was diagnosed over a decade ago, who's health have deteriorated to the point they require full time assistance with their every needs. We are not there yet, by a long shot, miraculously. We may never be there. But that's the issue: what I know now is that we really don't know much – there is a

lot of new and interesting work being done in the neurological world, the idea of Parkinson's not being one discrete syndrome but a multi faceted web of conditions affecting the mind and the body, moving towards the idea of multi-pronged interconnected treatment programs. I am so glad there are super smart people who spend their lives focused on the pursuit of ameliorating my husband's life, and who knows, sourcing a "cure." But what I know now is that, as much as we know, we know "nothing". I don't know what will happen in the future, I don't know how much my husband's health and condition will deteriorate, I don't know how his mind will be affected, I don't know if and when his cognition may slip. I'm terrified that one day, the drugs he takes now will not give him any more relief. And, what then? I just don't know.

How would my PD partner answer this question?

Again, I don't know how my husband would answer these questions. Part of my husband's amazing response to having PD is to have dived right in, into the community, volunteering, group leading, participating in every fundraiser, attending the socials, bringing people out who otherwise may not be able to make it out of their houses. He serves on a patient-advisory board at the University Health Network. He participates in research studies. He manages that part of his health that he can – he eats extremely well, sourcing healthy organic foods wherever possible, feeding his brain with healthy fats, exercises with discipline, treats our dog to daily roams in the ravines and off leash dales of our urban setting. He takes care of me, ironically.

So, my husband has developed a deep knowledge of PD, and the kinds of research and working hypotheses the scientific community is working with.

As the PD partner, he might have way more technical answers than me about what he knows now. My response is very emotional.

Alix Goulet



Alix and Gord in enjoying a lovely meal in Kotor, Montenegro

Alternative Therapies

Music Therapy

What is music therapy?

Music therapy is "a treatment including creating, singing, moving to, and/or listening to music [through which] clients' abilities are strengthened and transferred to other areas of their lives." (American Music Therapy Association)

Certified Music Therapists (MTAs) use music purposefully to support health and well-being. They use music to address human needs within cognitive, communicative, emotional, musical, physical, social, and spiritual domains. (Canadian Association of Music Therapists)

What are the benefits of music therapy?

Music therapies may play a role in treatment and management of Parkinson's and other movement disorders.

People with movement disorders often note that moving or walking to a rhythm helps improve their movement. Rhythmic auditory cueing is a technique in which rhythm is used to facilitate movement and improve gait. Music gives you a cue - the beat - and your body learns to move your feet to the beat!

Dancing and singing are also considered music therapies and provide many benefits. Dancing helps with balance and coordination and is great exercise! Singing can help improve voice quality and volume.

Music therapies can also increase socialization and may have mood and cognitive-boosting benefits. (ADPAParkinson.org)

How to find a music therapist?

The Canadian Association of Music Therapists shares a directory of music therapists. Click on your province, then use the "find a music therapist" function found there.



Canadian
Association of
Music Therapists

Association
canadienne des
musicothérapeutes

Musical things to try that can be beneficial and fun!

Choir! Choir! Choir!

Beats Medical Parkinson's App

Karaoke - get your care partner, family and friends in on the fun!

Try searching the name of a song on YouTube with the word karaoke at the end. SingKing is one option!

Testimonials for the music therapy program

Singing with Parkinson's



"I see an improvement in my husband's speech after we have a singing session which is one of the benefits of singing other than enjoyment and comradery."

~care partner to member of Singing with Parkinson's

"Singing with Parkinson's is a safe, friendly, warm and fun place where we can be ourselves, and enjoy life. The bonus is that I'm learning to control my breathing, leading to fewer problems while eating and drinking."

~David D. patient member of Singing with Parkinson's

"Our teacher is fun, optimistic and full of encouragement. She pushes us just enough, and makes us proud of ourselves. My family has, at various times, remarked that I seem like a happier person. Anxiety, depression and apathy are common symptoms of Parkinson's disease and this is a wonderful antidote."

~Helen M. patient member of Singing with Parkinson's

"The effects of ongoing group singing are beneficial on many levels. Voices, both speaking and singing, grow stronger; breath is better controlled as the expressive muscles of the face are exercised; there is a deep sense of belonging and communal support for people who might otherwise isolate; there is pride in feeling a sense of accomplishment as the brain is engaged with learning new songs and vocal techniques."

~staff member of Singing with Parkinson's



Share your experiences with us! Tell us what programs or therapies you find helpful. Email us at movementdisorders@uhn.ca



Resources for your vocals

Speech and vocal exercises are important for many types of movement disorders. Here are a few resources that can help.

Apps

LSVT Global LOUD

LSVT LOUD uses clinically-proven methods for improving communication and movement in individuals with neurological conditions.



Loud and Clear Speech

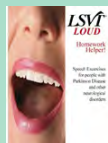
Over a four-week period in roughly 15 to 20 minute sessions, this app aims to help strengthen voice volume.



DVD

LSVT LOUD Homework Helper! DVD

This DVD takes you through voice and speech exercises based upon LSVT LOUD speech therapy.



Online Videos



SPEAK OUT! Practice Videos

SPEAK OUT! Practice videos guide you through daily exercises with Speech Language Pathologists.

Community programs



Singing with Parkinson's

Group singing can improve vocal strength, breathing and swallowing control. Register to take part on Zoom!



Louder, Clearer: A Parkinson's Voice Training Program

Parkinson Society Southwestern Ontario delivers group sessions led by speech-language pathologists.



Arts & Artists

*So many of you are talented artists, photographers, writers and musicians! We are delighted to feature your **creative work** and even your **travel photos and stories** in this section. Share yours at movementdisorders@uhn.ca*

This issue features beautiful Fall photos and a short biography by Julian Kocjan.



Niagara Escarpment fall colours / St. Catharines

My story

By Julian Kocjan

My movement disorder started 7 years ago. My left big toe started moving without my control. The timeframe to see a neurologist was 6 months or more, and I visited four of them. Tremor was the diagnosis given to me.

Over time, the tremor started progressing. I noticed that it started to affect my left hand too. Sometimes my leg would be moving on its own, then my hand. Right now, the tremor movement affects both my leg and hand at the same time.

Two years ago I was referred to Toronto Western Hospital. I saw Dr. Sarah Lidstone. Her diagnosis was tremor/Parkinson's. Currently I'm on medication, and I am able to see some help from taking it. With Dr. Lidstone's encouragement I'm doing a 20-30 min brisk walk daily, and biking as well. I also spend 30 min in the morning doing muscle stretches and some exercises standing up and laying on the floor.

With my daily routine, as long as I'm in motion, I can cope with the different tasks around the house. But my hobby for so many years, photography, is going slowly into jeopardy - especially when it comes to using my big 150-600 mm lens, which I use for extreme close ups.



Early morning fishing on Lake of Two Rivers in Algonquin Park



Selfie? Love it! Which button am I pushing? / Lake of Two Rivers, Algonquin Park



Fall time / Opeongo Lake, Algonquin Park

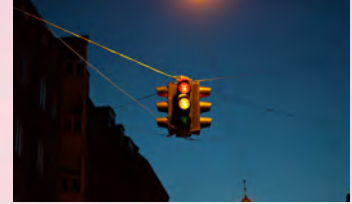
At your leisure

A few hand picked articles we think you may find interesting, helpful or thought provoking. Enjoy!

Double click
an image to
take you to
the article

How the body and mind talk to one another to understand the world.

Interoception is an interaction between body and brain, a sense that informs us about our internal bodily sensations. Things like the pounding of our heart, the flutter of butterflies in our stomach or feelings of hunger



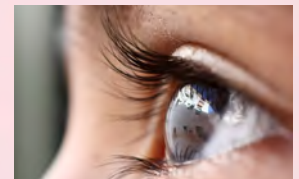
Study reveals how the brain overcomes its own limitations

If you're doing something that requires a hard mental transformation, with uncertainty and variability, you rely on your prior beliefs and bias yourself toward what you know how to do well, in order to compensate for that variability,



Perceptual Sets in Psychology

A perceptual set is basically a tendency to view things only in a certain way. Perceptual sets can impact how we interpret and respond to the world around us - and sometimes they can lead us astray.



Trauma, trust and triumph: psychiatrist Bessel van der Kolk on how to recover from our deepest pain

Author of The Body Keeps the Score talks about physiological changes that result from trauma. Stress is stored in the muscles and the brain's alarm system is recalibrated. The rational mind cannot do the repair work on its own.



Survey Results!

Thank you to everyone who completed our last survey! Here are a few things we learned:

- You rely on your **neurologist**, the **internet**, and **MDC Connections** for information about movement disorders. Sources you mentioned specifically:

“

- [Parkinson Canada](#)
- [Parkinson's Foundation](#)
- [PMD Alliance](#)
- [Johns Hopkins](#)
- [Cure PSP](#)
- [National Ataxia Foundation](#)

“

Other people with Parkinson's. Met at activities like *[Dancing with Parkinson's](#)*

“

Research articles from *[the Lancet](#)* and *[Neurology](#)*

- You like to hear about our **research**, to be informed about **resources**, and you find the **patient stories** especially useful. Some of your comments:

“

Please keep *MDC Connections* coming! So full of information

“

I love it all

“

This is an excellent publication with very useful information

“

Would like to see expansion of articles on art therapies

“

Patient experiences that are relevant for learning or simply patient experiences that I can relate to

“

Bravo team!

MDC Research Program

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* within the last 5 years, not taking any medications for it. Contact us for details.

→ If you have Parkinson's, are experiencing bothersome pain, and are interested in hearing more about the *Cannabis* study we'd love to hear from you! You must not be currently using Cannabis.



→ Parkinson's patients and family members needed for a study investigating differences in 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.

→ The *PPMI* study is looking to identify risk factors and markers of disease progression. It's open to anyone with Parkinson's disease (PD) who are not taking any medications for it. Your symptoms will be tracked over time and periodic biosamples will be collected. Let us know if you're interested!

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! Find a list of research studies [here](#).

Recently published research by MDC Faculty

Exposure to Phosphoglycerate Kinase 1 Activators and Incidence of Parkinson's Disease.

Gros P, Wang X, Guan J, Lang AE, Austin PC, Welk B, Visanji NP, Marras C.

Study results suggest certain drugs used to treat prostate conditions may help to reduce men's risk of Parkinson's disease (PD). Researchers looked at terazosin, doxazosin, alfuzosin and tamsulosin - drugs used to treat enlarged prostate. They found that all four drugs were associated with a lower risk of developing PD in men over the age of 66.



MDC Media & Events

The 2021 Krembil Brain Institute magazine features cutting edge research by several MDC Faculty!



Missed the October 2021 Speaker Series on Cannabis with Dr. Fox and Dr. Lang? Watch the recording!



THE MOVEMENT DISORDERS CLINIC PRESENTS

Stimulating Brain Discussions on DBS

November 3 and December 8 | Zoom Webinar

A series of talks devoted to answering your questions
about Deep Brain Stimulation (DBS)



NOVEMBER 3, 2021
6:30 PM - 8:00 PM

Are you thinking about
undergoing DBS?

DECEMBER 8, 2021
6:30 PM - 8:00 PM

Did you have DBS and
want to share your story
and hear about others'
experiences?

REGISTER ONLINE AT

https://events.myconferencesuite.com/DBS_PatientEd_2021

Telemedicine and COVID-19

How MDC made the switch

By Dr. Gerard Saranza. Interviewed by Julie Racioppa

When COVID-19 had us in lockdown in March 2020, virtual care became a necessity, quick. Throughout UHN more than 50% of outpatient clinic visits shifted to virtual care, consisting of either video or telephone calls.

Dr. Saranza was a Fellow at the Movement Disorders Clinic for the first 8 months of the pandemic. He is now working in his hometown of Cebu, Philippines as a Movement Disorders Neurologist.

Dr. Saranza, you were instrumental in MDC's pivot to virtual care. What were your thoughts when the pandemic struck, and you realized this was a necessary shift?

The pandemic came as a big surprise to humanity; nobody was prepared for the total lockdown. Some clinics in Toronto opted to close for a few weeks while waiting for the situation to improve. However, knowing that most of our patients at the MDC belong to the high risk group for severe COVID-19 infection, the MDC staff decided to continue offering services to our patients in whatever way possible while ensuring the safety of everyone. Doing only teleconsultations for several weeks was quite a challenge for many who were not used to doing it routinely before the pandemic started. Fortunately, many of us were technology savvy and had no major difficulties doing virtual care. However, many of our elderly patients were not comfortable doing the videoconference type of teleconsultations. We had to meet regularly to discuss the changes in our clinic services and the challenges each one encountered. We had to constantly implement ways on how we could further improve the experience for the patients, and the administrative and clinic staff.



Dr. Gerard Saranza at MDC



MDC Fellows: Drs. Bhowmick, Saranza, Gonzalez-Latapi, AlShimemeri, Azevedo, Al-Shorafat, Kuhlman, Sousa, Couto, and Mendez



Anthea, RN, Dr. Al-Shorafat, Ann Marie, Tiffany, and Dr. Saranza

Were there any major issues? How did patients react?

Based on the survey that we conducted, most of our patients were grateful that the MDC continued to provide services throughout the total lockdown period. The majority considered telemedicine to be just as good as a traditional in-person visit (see table). Our patients continued to have appointments with their doctors at the comfort and safety of their homes, especially during the first few months when everyone was still trying to figure out how to handle the COVID-19 infection. Difficulties and issues were inevitable, especially during the first few weeks. Getting regular feedback from our patients and from the administrative staff and clinic staff helped us recognize the strengths and weaknesses of the system we implemented. For example, one major issue raised was the patients' difficulty navigating through the teleconsultation platform. We addressed this by creating a patient guide (see figures) that we provide to our patients to help them prepare for their teleconsultation.

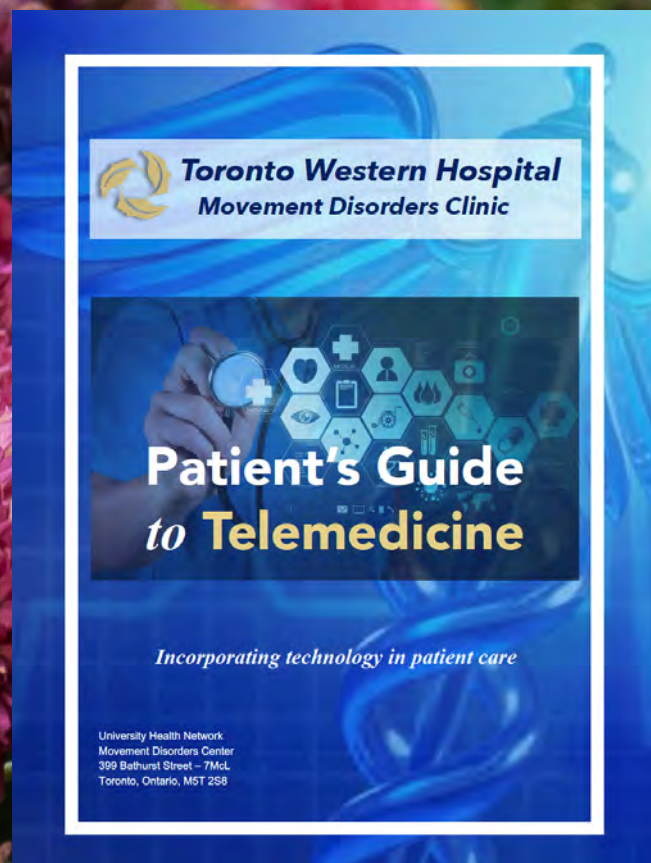
Now, after 18 months, how do you think virtual care has shaped the world of medicine?

Traditional healthcare delivery has challenges, such as limited physician-patient ratio, geographical barriers, and the concentration of specialists in cities. These limitations make it difficult for a good proportion of patients to avail of healthcare services, especially those with severe physical limitations. Thus, it was already predicted that telemedicine would be utilized more in the next decades, even before the pandemic began. The pandemic has created a unique situation where the physicians and patients were left with no choice but to utilize telemedicine for the continuity of medical services. It made us realize that virtual care is indeed feasible, reliable, adequate and efficient, although admittedly, it also has limitations. I have no doubts that telemedicine will be routinely incorporated in healthcare delivery even in the post-pandemic period...should this pandemic come to an end!

Response	Percentage	Breakdown
Better than a traditional in-person visit	9%	<ul style="list-style-type: none"> • Phone: 50% • OTN: 33% • Phone + OTN: 17%
Just as good as a traditional in-person visit	50%	<ul style="list-style-type: none"> • Phone: 44% • OTN: 44% • Other platforms + Phone: 3% • Other platforms: 9%
Worse than a traditional in-person visit	30%	<ul style="list-style-type: none"> • Phone: 74% • OTN: 11% • OTN + Other platforms: 4% • Other platforms + Phone: 11%
Not sure	1%	<ul style="list-style-type: none"> • Phone: 100%

Table showing telemedicine is considered just as good by MDC patients

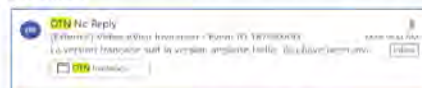
Figures from the MDC created *Patient's Guide to Telemedicine*



II. Scheduling an OTN Appointment

How is my OTN visit going to be scheduled?

When the front desk staff calls you for your appointment, they will inform you that your appointment will be conducted through OTN on a specific date and time. They will ask for your **VALID email address**, preferably a **personal email address** as corporate emails are not ideal to share private health information. Shortly thereafter, an **invitation** will be sent to the email you provided as in the figure below. **You do not need to reply to this email.**



The body of the email contains important details:



Instructions on how to connect to the OTN interface. Instructions are available in English and French. **Please read the instructions carefully ahead of time to avoid any technical issues during your OTN visit.**



What if I do not receive an email regarding my appointment?

First, check the **spam/ junk folder** as the email invitation might have been directed there. If you still could not find it, please call **Ms. Annie Prokopowich** at 416-603-5800, Ext. 5307. You may also email her at Annie.Prokopowich@uhnresearch.ca.

If you are a patient of the DBS clinic, please call 416-603-5800, Ext. 5729 or you may email the DBS staff at DBSAdmin@uhn.ca.



III. Preparing for an OTN appointment

Before your OTN visit...

- Although not an absolute requirement, please ask a caregiver to help you set up the OTN interface and to assist you during the OTN visit.
- Please **make sure that your telephone and mobile phone lines are open**. Your doctor might call you through your telephone or mobile phone should there be a connection problem (please see page 8 for further details).
- Please **avoid sitting with a window or another light source behind you** because this will prevent your doctor from seeing you clearly.
- If you need a walking assistive device (e.g., walker, cane, etc.), please keep it close by. You might be asked to walk during the physical examination.
- If possible, **please be in a room with enough space to walk**. Gait examination is an important part of the physical examination.
- While pets are cute and adorable, please make sure that they will not interfere with the gait examination. It is best to keep your pets away from you during your OTN visit.
- Keep a piece of paper and a pen close by** for further tests that your doctor might ask you to do or for you to take down notes.
- If you are a patient who underwent DBS, **please have your remote control near you**. When able, please check your battery pack on the day of your OTN visit.
- Please **keep your medication list ready**.
- Prepare the **telephone and fax number of your pharmacy** because your doctor will ask this at the end of the visit.



Research papers for further reading on Covid-19 and Telemedicine

Management of Advanced Therapies in Parkinson's Disease Patients in Times of Humanitarian Crisis: The COVID-19 Experience
Fasano, A. et al. Movement Disorders

Telemedicine and Deep brain stimulation - Current practices and recommendations
Sharma, Vibhash D. et al. Parkinsonism & Related Disorders

Thanks for reading!

We love to share your stories, tips, recommendations, anecdotes, testimonials, research experiences, photos and artwork!

Let us know what you want to see more of. Feel free to email us at movementdisordersclinic@uhn.ca



Looking for more resources and information on movement disorders?

➔ *Check our past editions of MDC Connections.*

- [Summer 2021](#)
- [Spring 2021](#)
- [Winter 2020/2021](#)

PDF's can be downloaded [here](#).

Sign up [here](#) to receive future issues directly in your inbox!

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Toronto Western Hospital

399 Bathurst St.

Toronto ON M6J 3S8

416 603 5800

[MovementDisordersClinic \(uhn.ca\)](http://MovementDisordersClinic.uhn.ca)

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