# MDC CONNECTIONS

SUMMER ISSUE 2021

## For all the caregivers and care partners!

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Helping you maintain momentum with powerful resources is our priority.

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# *Welcome*

Welcome to the third 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*

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

UHN Movement Disorders

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# *Connections*

We read and listen to all of your feedback! One of the suggestions you made was for more information on caregiver's concerns and what support is available. Caregivers are often a neglected part of the care team, yet they are doing a tremendous amount of health care. Receiving a diagnosis of a chronic illness is a life-changing experience not only for the person with a movement disorder but for the spouse, child, grandchild, parent and friends as well. This issue is for all the carers out there!

Over our lifetime we experience many changes some of which are exciting and some that are challenging. While we are resilient and adjust to the challenges, we can all use guidance, tips and support.

***A chronic, degenerative disease is unexpected and although you didn't choose the role of carer it is something you do because of your love and commitment.***

As the disease progresses the responsibilities on the carer increase and can result in significant stress. In this issue we emphasize that the earlier we learn what to expect, the earlier we can be fully prepared for the challenges to come. We recommend that you educate and engage family and friends to create a support network that allows the primary carer to take time for themselves to make their own health a top priority.

In this issue you will hear from Linda, a care partner for 22 years. She describes the four stages of her husband Don's Parkinson's and the resources that helped her. You will also hear from Don's friend Charlie and how their friendship kept alive a meaningful social connection while at the same time providing relief for Linda. Murray's family story describes how a circle of communication helped their family and friends interact with his mother.

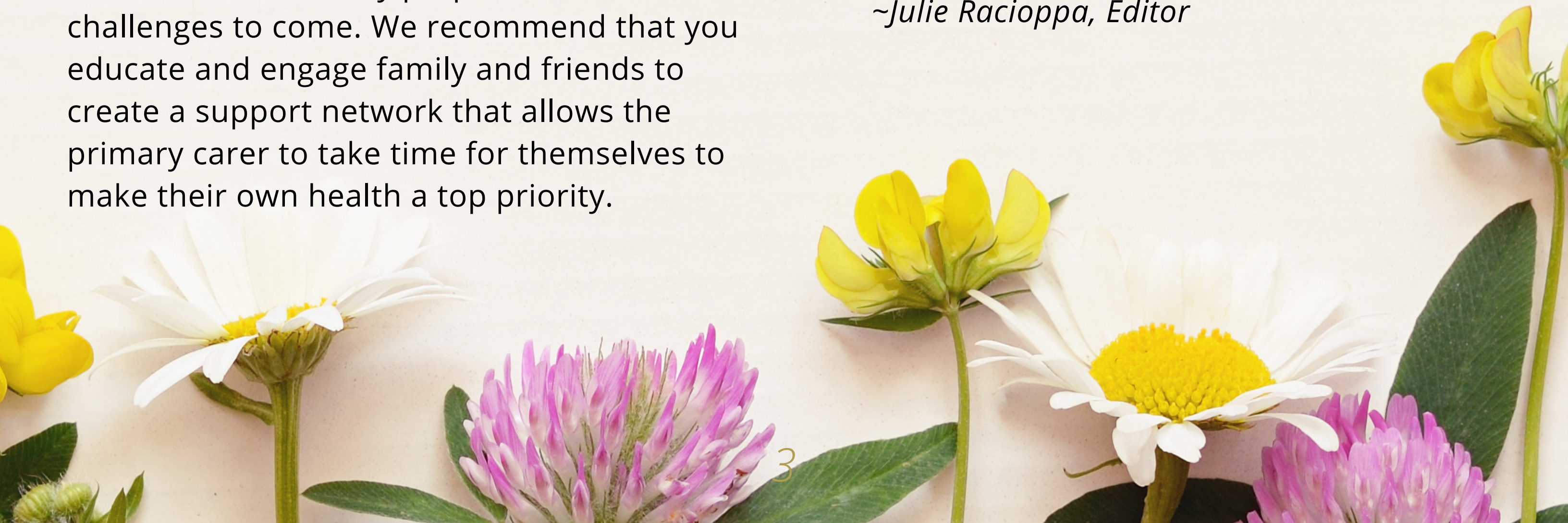
## ***Find an exercise buddy!***

Haseel Bhatt, our Physiotherapist talks about the role of an exercise buddy to help stay focused on the all-important daily exercise routines. We also provide links to reliable websites and resources that provide information, support and tips for carers.

*"And so with the sunshine and the great bursts of leaves growing on the trees, just as things grow in fast movies, I had that familiar conviction that life was beginning over again with the summer."*
*~F. Scott Fitzgerald, The Great Gatsby*

Wishing you and yours many long, fulfilling and rejuvenating summer days. Stay safe.

*~Linda Redford, Care partner and Guest Editor*
*~Julie Racioppa, Editor*



# Tech Help

*Think twice before you print! This e-newsletter is made for technology. It works best if you view it on a computer, laptop or tablet. Anytime you see something **bolded** or underlined click it to take you to a website! TIP: Right click to open a link in a new window so you don't get booted back to page one when you close the website.*

## Trouble viewing the newsletter?

Try increasing the magnitude on your device.

Here's an easy way to do this on a laptop or desktop:

- Press **ctrl** and **+** to zoom in.
- Press **ctrl** and **-** to zoom out.
- Press **ctrl** and **0** to return to the default setting.

Not on a laptop or desktop? Try Googling "how to magnify the screen on *insert the name of your device"*. Or try asking your device, literally!

## Virtual Visit help guides

UHN Toronto General Toronto Western Princess Margaret Toronto Rehab Michener Institute

**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.

**Ontario Telemedicine Network** (OTN) troubleshooting and help guides can be found here.

## Need help with technology?

Want to virtual chat but need help setting up FaceTime / Skype / Zoom? Want to learn how to listen to music on the internet? Or how to send photos via email? Connected Canadians can help. They offer one-on-one custom training for various technology challenges!

# *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. Challenge yourself and see where it takes you!*

**For care partners and caregivers**

**Lotsa Helping Hands**

Coordinate and schedule care, meals and appointments with a shared care calendar. Options for messaging within the support team and a shared photo gallery.

**To get you moving!**

**ZWIFT**

**MDC staff rave about this!**

Chase your goals with Zwift! Without worrying about traffic lights or stop signs you can jet across the desert or climb a volcano with this virtual cycling, goal setting and community oriented app.

**Goal setting and productivity**

**Mindful Browsing**

Set goals around which websites you'd like to spend less time on. It will gently nudge you, checking in to remind you that, hey, you said you'd rather not be doing this, remember? Options for adding self-care reminders, such as breathing exercises or going for a walk.

**For your wellbeing**

**healthyminds innovations**

The Healthy Minds app uses a combination of podcast-style lessons and both seated and active meditations. Learn what the science says about the brain while developing skills and tools for everyday life.

# *Ask the Neuro PT*

*By Haseel Bhatt, PT*

*Welcome to our new column featuring our esteemed neurological physiotherapist Haseel Bhatt. He will answer your questions about exercise, physiotherapy, motivation and more, giving us his expert, evidence based advice.*

## *Movement with Meaning - How connection helps you move more*

Part of self care is movement, and part of care partnering can be encouraging your loved one to move more. Social engagement (connection) and support from family and friends can be a motivating factor. An exercise partner can be a positive influence, they can help hold you accountable!

***"How important are care partners when it comes to helping a loved one exercise"?***

Connections and care partners are extremely important when it comes to exercise. In fact, research has shown that the enjoyment that comes from the social interaction when exercising with a friend, family member or community group is an important factor that motivates people to start and keep exercising. Having an exercise partner in a loved one, can make exercise feel less daunting and keeps everyone accountable. Identifying which types of activities and exercises you and your loved one would enjoy and could potentially do together is a good place to start.

***"How can I continue to exercise? I get bored. I can't seem to keep myself accountable".***

Adding variety to your exercise routine can not only keep things interesting but is actually beneficial. There are tremendous benefits to adding components of aerobic exercise, strength training, balance training and stretching to your current exercise routine. I also recommend engaging in non-structured physical activities such as dancing, gardening and walking which can be done with a friend or family member and requires many of the above exercise components. Using apps such as Participaction, Strava and iPhone Health can also be helpful in keeping yourself accountable and motivated and often include weekly exercise challenges and games that allow you to compete alongside people in your social network and remain connected.

***"My loved one gets tired easily making it difficult to engage in social and physical activities. What can I do?"***

Fatigue is common but can present differently in each person. Helping your loved one track their fatigue levels over the course of a week may reveal patterns of high and low energy. For some people this may be linked to the time of day and for others it may be associated with the timing of their medication. Engaging in social and physical activities during times when your loved one is feeling more energized, can make these activities more enjoyable and manageable.

*The statements above do not replace specific advice from your doctor or physiotherapist.*

# *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**<br>2 times per week | LEISURE WALKS | BRISK WALKING | BRISK WALKING WITH HILLS |
| **Strength Training**<br>2-3 times per week | CHAIR EXERCISES | SEATED STRENGTH TRAINING | SWIMMING |
| **Balance Training**<br>2-3 times per week | TIGHTROPE WALK | TOE THE LINE | FLAMINGO STAND |
| **Flexibility**<br>2-3 times per week | SEATED STRETCHING | MAINTAINING YOUR GARDEN | PILATES |

# One Care Partner's Twenty-Two Year Journey

*By Linda Redford*

My husband was diagnosed with Parkinson's twenty-two years ago. I fell in love with and married Don and we are life partners. As Parkinson's progressed, Don needed more care both physical and emotional which caused an increasing workload. Experts frequently say “take care of yourself”. That isn’t always easy, it is in fact very challenging! However, understanding the difference between my role as Don’s partner and the role of professional caregivers helped me to carve out time for myself to continue doing things that I enjoy.

***"Over the last 22 years I have seen Don go through four different stages."***

The first 9 years the Parkinson's symptoms were minor and life went on with no changes. In **stage two** the symptoms became more noticeable. I contacted Parkinson Canada to learn facts about the condition and to understand what to expect. Our life went on. Don continued the job he loved writing a trade magazine for Cinematographers. We enjoyed travelling; one trip to Hawaii and a train journey from Calgary to Vancouver were two favourites. I was aware that things were changing but the adjustments were minor.

***"My clarity about the difference between a care partner and a caregiver became extremely important."***

In **stage three** Don’s care needs increased. I was facing the 24/7 reality that I needed to manage all the household chores; everything from shopping, cooking, paying bills, making decisions and everything in between. Don’s day to day physical support needs increased. On the emotional side I willingly accepted that I needed to be Don’s social secretary, to make sure his connections with family and friends were maintained. It made me happy to see him joking, laughing and connecting with family and friends.

I contacted the Community Care Access Centre (CCAC) to assess Don’s condition. They provided Personal Support Workers (PSW) to help us with basic needs. I was able to privately access extra PSW hours to spend time with Don which gave me more free time. At first the PSW would walk with Don to the local manicure shop or hairdresser. He needed a walker for support but he was basically active. They would make his lunch, ensure he did his voice exercises and play checkers with him. Twice a week someone would help him bathe safely.

*Loving hugs from Don's daughters*

Eventually in **stage three** the non-motor, emotional symptoms became the bigger challenge. There was a decline in Don's executive thinking skills. Planning and decision making became more difficult. Depression and apathy were taking their toll. Apathy had taken hold and he didn't want to make the effort to go out. Luckily I was able to arrange for the hairdresser and the manicure specialist to come to our home. But after some months Don got to the point that he didn't even want to come downstairs to visit with people.

"***Don was becoming increasingly isolated. Keeping him emotionally involved was getting harder.***"

When family invited us to their home Don would look forward to the event until the actual day. Apathy and anxiety about a one hour drive on the highway would present a huge challenge and he would resist going! Luckily I was able to remind him how much fun he has with family and how much he enjoyed people laughing at his jokes. One step at a time, with gentle nudging I would get him dressed and into the car and off we would go. Sure enough, once there, he would thoroughly enjoy the visit.

As we neared the **fourth stage**, 19 years after diagnosis, Don and I talked about his increasing needs. It mattered to him that he not be "a burden" to me. We realized that a Long Term Care facility was the next step and that has proved to be a very good decision for us.

***"At his long term care home Don has "an army" of people who tend to his needs, physical and emotional."***

I am able to be his life partner, able to play games, attend music concerts at his home and laugh together. He gets visits from family and friends; we go to a local park, play ping pong, blow bubbles and get ice cream on the way home. The caregiving is done by professionals, caring people that have become friends. Before COVID-19 his favourite activity was the twice weekly art program. It turns out that he is a good painter.

*Don discovering a newfound talent*

*Painting by Don*

I have come to appreciate the Serenity Prayer. Don and I have done our best to be resilient and maintain meaningful activities but as the disease progressed it was important to accept that some things had declined to the point where they could not be changed. I had to let go and narrow my focus to what was still possible.

> ***Grant me the Serenity to accept the things I cannot change; Courage to change the things I can; and Wisdom to know the difference.***

# *My recommendations for every Care Partner:*

***Learn about the symptoms****.* It is important to understand both physical and emotional symptoms early after the diagnosis. Knowledge is power and will help you understand what to expect and how to implement support routines that will become increasingly important as the condition progresses.

***Educate and engage family and friends.*** It takes a village to care for someone with a chronic, degenerative disease. This issue of *Connections* includes two articles that describe how family and friends can contribute to the person's quality of life – and – share the responsibilities of caring for someone with a degenerative condition. People want to help once they understand what help looks like. Their help reduces the stress on the primary carer.

***Establish your own support system.*** Have a conversation with your own friends and ask them if they are willing to support you over the long term. This could include identifying roles for them. One friend might be your exercise buddy. Another might be the one that gets you out to enjoy dinner and laughter with friends at least once a month. Another might be the one to make sure you are making time for massage or other relaxation activities.

***Establish healthy routines as early as possible.*** Every expert I have heard speak emphasizes the importance of exercise. Developing an exercise routine for your partner, even before it is obvious what is needed, can mean that the person maintains physical mobility for as long as possible. Involve a family member or friend to be your partner's exercise buddy to relieve the care partner from that responsibility. Make this a top priority, it will pay huge dividends.

***Join a support group!!*** What a life saver it has been for me to attend a care partner support group, every month over the last 13 years. I get to vent my frustrations. I get to laugh at myself and survive the enormous challenges, physical and emotional that I have experienced. I learn so much from other people's experiences. I learn what I should observe about my husband's stage and what questions to ask of his health care team.

# *The Contribution of a Loyal Friend is Beyond Measure*

*By Charlie Campbell and Linda Redford*

Don and I contacted his closest friend Charlie not long after his diagnosis. It was a relief to hear that Charlie was "in it for the long term". I asked Charlie to attend a care partner support group meeting so he could hear from others what being a care partner involved. Charlie has been a valuable resource to help us make important decisions. When LTC was on the table, Charlie helped us think through the options and provided emotional support for Don. When Don was still able to travel to Florida for spring training I got a week off from caring responsibilities.

***"That was a vacation I really appreciated!"***

*Here is Charlie's story about their friendship.*

Just arrived in Canada in 1982, I (Charlie) was assigned an office next to Don. We soon discovered a shared love of baseball, and Don has been my closest friend ever since. We watched games together from the fifth deck of the Toronto stadium and explored Florida's back roads year after year in March, once managing to squeeze nine spring training games into a seven-day trip.

"***Don's Parkinson's diagnosis in 1999 gradually changed the rhythm of the spring training baseball trips."***

Longer scheduled naps were needed, shorter walks to special parking access and eventually, wheelchair seating. Over the years, Don would often worry about what his disease would mean for his future, but beyond acknowledging uncertainty, there wasn't much to say, and there were plenty of other things to talk about.

Once Don moved to Chester Village, a weekly visit for a televised baseball game anchored our relationship. Don needed ever greater encouragement to get out and do the things he still enjoyed. For much of the past year, pandemic restrictions have narrowed the connection to the occasional phone call, which is less than ideal. Don's speech is sometimes hard to understand so calls might only manage to cover a review of the latest Blue Jays news, a reminder of the upcoming game time and a promise to call again soon.

My second vaccine shot is scheduled for July. I'm hopeful this third wave of COVID will be the last, and we'll be back to watching ball games together, playing Chinese checkers and making the occasional outing with Linda. After this very long pandemic winter, it's something to look forward to.

*Don and Charlie are devoted Blue Jay's fans!*

# *Caring for Carers*

*Research shows that personal care is usually given the least attention when it is needed most. When we are depleted or overwhelmed we have little energy to devote to ourselves. With self compassion and humility we can move past the stigma of doing it all and check in with ourselves.*

### Forgive yourself for not being perfect.

Accept your own humanity. Give yourself a pat on the back for doing the best you can.

### Accept that you may feel emotionally off-balance.

Recognize the hidden grief component of anger, anxiety, guilt or depression. Expect that you will adapt, but may not find resolution to your grief. Accept it and seek out someone who understands.

### Determine your limits.

What is your comfort level providing care? Everyone has limits. What are yours?

### Make regular breaks from caregiving a priority.

You cannot be a good caregiver to someone if you do not take care of yourself. Your loved one can survive a few hours and, periodically, a few days without you.

### Be kind to yourself.

Remember you are experiencing normal reactions to abnormal circumstances.

### Seek out joy in your relationship.

Add some fun to your hands-on care: sing songs, tell jokes, share goals and dreams.

### Develop a habit of participating in activities together outside of care giver/care partner roles.

Shared time as husband-wife, mother-daughter, siblings or other relationship – rather than as care giver and care recipient, or care partners – allows you to enjoy each other and build happy memories.

### Try to forgive your loved one for past hurts.

Resentment toward past wrongs and injustices will make your present caring role difficult. Let go of what was, and make what is, healthy and productive.

*Adapted from the Parkinson's Foundation Caring and Coping book*

CAREGIVER ACTION NETWORK CAN

The Caregiver Action Network (CAN) provides education, peer support, and resources to family caregivers. Here are a few places to get you started:

- Family Caregiver Toolbox
- Care Community
- Top Ten Tips for Caregivers

CAREGIVER HELP DESK 855-227-3640

# *Caregiver/Care Partner Resources*

*The following are support resources for caregivers, care partners, spouses, family and friends. You are not alone.*


I am a Caregiver

Getting Started Toolkit

THE ONTARIO caregiver ORGANIZATION | RESOURCES AND EDUCATION

There are many commonalities across illness and disease for caregivers. The Ontario Caregiver Organization Getting Started Toolkit was created by caregivers, with information for both new or seasoned caregivers.

The Ontario Caregiver Organization has a **24 hour Caregiver Helpline** **1 833 416 227** or live chat during the week 9am - 7pm.

variety the children's charity of ontario

Variety Village is a community for people of all abilities. They identify as a children's charity focused on fitness, sports and skill development, but they also have wonderful adult day programs for anyone over the age of 21 with a physical or developmental disability.

MARCH OF DIMES CANADA

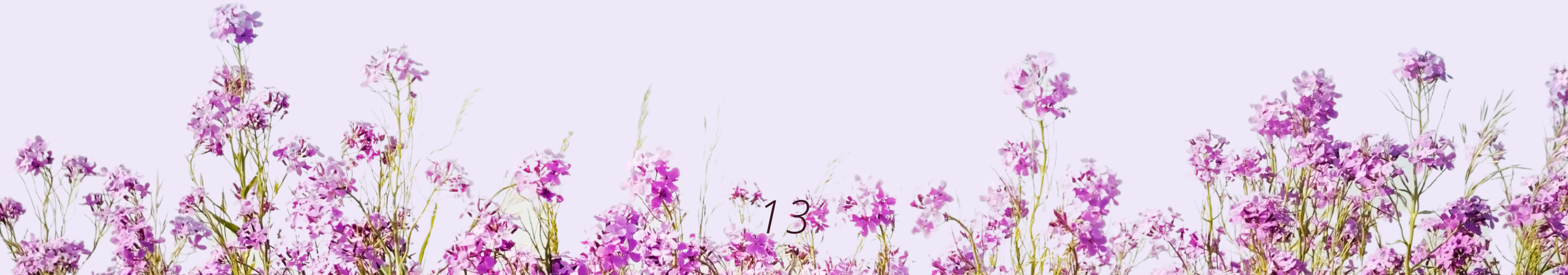
March of Dimes provides a wide range of services helping people with physical disabilities maintain independence, personal empowerment and community participation. They have shifted to virtual and have a number of programs for caregiver support.

Ontario

Local Health Integration Network (LHIN) provides home and community care support services and will link you to providers in your area. Explore your options through their website or call the main phone number 310-2222.

THE NEIGHBOURHOOD GROUP
NEIGHBOURHOODS WORKING TOGETHER

The Neighbourhood Group, formerly the Neighbourhood House, provides in-home services like housekeeping, personal care and respite for seniors with physical disabilities. Contact them to find out what support is available for you.



# *Caregiver/Care Partner Support Groups*

*The following support group resources are for caregivers, care partners, spouses, children, family and friends of people with movement disorders.*

## ATAXIA

- **Facebook Group: Spouses and Partners of Loved Ones with Ataxia**
  Email: ataxiafacts@gmail.com

## DYSTONIA

- **Facebook Group: Caring4Parents with Movement Disorders**
  Email: contact@dystonia-foundation.org to join the group.
- **Facebook Group: Dystonia Spouses and Loved Ones**

## LEWY BODY DEMENTIA

- **The Lewy Body Dementia Association has phone support for caregivers 800-539-9767**
- **Facebook Group: Lewy Body Dementia Carers**
- **Email support community: LBD Caring Spouses**

## PARKINSON'S

- **Parkinson Canada hosts virtual support groups, some are specific for care partners.**
  Use the locator to find one or call them for information 416-227-9700
  Toll Free: 1-800-565-3000

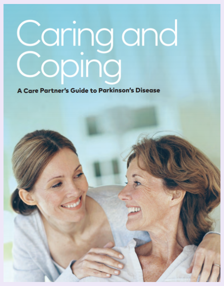
*Our Spring 2021, issue has information on support groups for other movement disorders. See page 21*

# *Parkinson's Caregiver/Care Partner Resources*

*The following resources are for caregivers, care partners, spouses, family, friends and people with Parkinson's. Take a look!*

Parkinson Canada

Care Partnering, Managing Parkinson's Disease Together is a support resource with information, stories, tips and worksheets.



Parkinson's Foundation

Caring and Coping: A care partners guide to Parkinson's disease helps prepare you through the journey of caring for someone with Parkinson's.

Being a care partner is a challenge in many ways. Stepping into the role can cause stress, compassion fatigue and caregiver burnout. Learn strategies to preserve your mental health as you support your person with Parkinson's in this webinar: Mental wellness for Parkinson's care partners - with Elaine Book, MSW, RSW

DAVIS PHINNEY Foundation For Parkinson's

More resources for care partners from the Davis Phinney Parkinson's Foundation can be found here.

Getting Real!™ Online is a virtual community for **care partners, adult children and family** that includes an educational video library covering topics from symptoms, practical tips for management and support.

Register here to be part of this online community.

An Inside Look at Being a Parkinson's Care Partner by Parkinson's Disease.net offers tips for self care, managing stress, long-distance caregiving, strategies for when a loved one refuses care, and more.

# *Patient Perspective*

## *A Communication Circle of Family and Friends Maintains Social Interaction*

*By the Boyce Family*

Margaret was diagnosed with Multiple System Atrophy (MSA), a progressive, neuro-degenerative disease, marked by a combination of symptoms affecting movement, blood pressure and other bodily functions. MSA also interferes with the automatic aspect of speech and can result in communication difficulties including a quiet voice, slurred speech, and a stuttering-like fluency.

*Margaret at her 80th Birthday celebration*

Margaret was most definitely a very social person; a terrific listener, story teller and had a large number of close friends that she kept in contact over the years. She hosted family meals, her annual Christmas soup luncheon, bridge parties and entertained friends at the farm.

***"There's magic in her eyes!"***

Several folks have told me that they remember my mother with a twinkle in her eye...and it's a lovely true memory...she might have been greeting hello or saying thank you or smirking at your joke...But a twinkle was often there.

Margaret's drive and headstrong approach to just getting on with life both delighted and blew away her doctors and those around her. Her selfless generosity prevailed.

***"Though Mom's physical condition deteriorated over time her plucky, do it yourself attitude never changed."***

The greatest sadness my mother experienced with MSA was difficulties communicating. It was frustrating not to be able to pick up a pen and write a card to a friend, and over time, talking became difficult and hard to understand. To someone who valued being in touch, wishing pals happy birthdays, having a good old gab...this was tough.

The family contacted Bonnie Bereskin, a speech-language pathologist, who introduced Margaret to the Lee Silverman Voice Treatment (LSVT), an intensive program of voice therapy with practice exercises to strengthen vocal cords, breath control and voice. Margaret also needed help controlling the rate of her speech so exercises aimed at slowing down the rate of speech were introduced. The exercises would only be effective if practiced regularly and it quickly became clear that Margaret would need support.

***The family established a Communication Circle with Margaret's caregiver, three generations of family and several close friends to support an ongoing speech therapy program.***

*Margaret and her caregiver Sheila*

The Communication Circle was established as a way to maintain her speech as long as possible and as a preventative step to reduce the risks of depression and apathy that are often symptoms of MSA. It was also a proactive step to introduce more social interaction.

An important reality was that family and friends were at risk of feeling discomfort visiting someone who was increasingly hard to understand. The speech therapy program provided an added bonus – a purpose for family and friends to be involved. It is common that family and friends want to help – but – they often don't know what help looks like.

***The introductory Communication Circle session provided education to the team, teaching them about the symptoms and characteristics of MSA.***

Then came the voice rate and control training. People learned to cue Margaret to use pacing to improve intelligibility and pushing exercises to help strengthen the closures of her vocal chords.

After the training, the Communication Circle resulted in more frequent and meaningful visits by grandchildren and close friends. Margaret was not only able to improve her communication skills on a regular basis but also enjoyed and looked forward to more frequent and regular social interaction with family and friends.

***The regular contact allowed family and friends to adjust to the symptoms of the disease and overcome any discomfort they would have otherwise felt with the physical and cognitive changes.***

I know that Mom felt good doing the exercises knowing that without them her voice would continue to weaken. I enjoyed doing them with her because they made us laugh and I too felt that I was helping in some way. The visits with friends like Isabel, kept her social calendar a little more filled with visits that otherwise would not have taken place, at least not as frequently.

There was definitely value added to Mom's life with her family and friends dropping by more regularly. I know friends enjoyed going to see mom every week. That would not have happened without the Circle. I definitely benefitted from learning how to communicate with Mom after she lost her voice completely with tactics given to us by Bonnie.

*Margaret and her close friend Eleanor*

# *Resources*

LSVT LOUD is an effective speech treatment for people with Parkinson's and other neurological conditions.

Find a certified clinician here.

Bonnie Bereskin, Speech-Language Pathologist describes how communication circles work, the benefits, and how to create one in this article featured in e-ParkinsonPost.

Learn about MSA, the latest research, and find reliable resources for caregivers, family and friends.

Information about the signs and symptoms, causes and treatments for MSA.

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

*By Gordon Myers*

*When we have a strong foundation of routines unexpected changes can't easily throw us off course. It's important to be educated to learn what changes to expect as the disease progresses. When we know what to expect we can implement routines early that are the foundation of support that will be needed, even if those routines aren't needed for 10 years. Engaging family and friends early on can make it easier to deal with these challenges.*

*The following feedback is from members of a Parkinson's support group.*

Full disclosure, I'm a 64-year-old man who was diagnosed with Parkinson's disease 11 years ago. My PD has progressed slowly, especially as far as the classic motor symptoms go, and I seem to respond pretty well to the standard meds. As a result, I've remained as physically active as pre–Parkinson's Gord but, as my wife and care partner would attest, and a prematurely halted career in music would confirm, I don't quite work as well as I used to.

One of the things I can do though is facilitate a Parkinson's support group, so in preparation for this edition of the newsletter, I asked a few care partners the following questions:

***1. What's the most significant thing about being a PD care partner that you know now but didn't see coming 10 years ago?***

Responses to this question varied as much as the PD path does from person to person. What you'd think would be a very treatable symptom like abnormally low blood pressure turns out to be the most persistent and bothersome surprise symptom for one patient whose mobility and confidence have been dramatically affected by hypotension. The pace of the diseases' progression when the "honeymoon is over" (refers to the first 5 to 10 years after diagnosis when symptoms are relatively quiet) is a surprise and serious concern for both patient and care partner. None more so than a care partner whose husband, diagnosed at age 39, skipped the honeymoon and went right to rapid progression and at 9 years in, is looking at 24-hour home or long-term care. None of the literature they read warned of this rapid a progression. Her husband is, "lucky if he has 20 minutes of good time per hour."

Another person found the move from care partner to care giver hard to accept and was particularly surprised by how dramatically non motor symptoms like speech, cognition, incontinence, drooling... worsened. "I had not expected that I would essentially lose most of my life, and myself, to this disease and that life would become particularly lonely."

***2. How would your PD partner answer the same question?***

Care partners have an essential and unique insight into their partner's state of mind and thought processes. In the good years (the honeymoon) their role is not so different from any other spouse living their life in a happy (hopefully), supportive team. As the disease progresses the care partner's role gradually becomes caregiver, life coach, financial planner, health care coordinator and, and, and… In response to the above question the care partners, in one way or another, imagined their PD partners loss of independence as the biggest thing they were least likely to see coming. For one it was the inability to work at a high enough level to continue doing the job they had done quite successfully for many years. Another found technology frustrating and stressful. As the care partner whose husband has a particularly aggressive form of PD describes, “I have watched the most brilliant man I know who was also physically fit deteriorate rapidly. His career was destroyed, and he can hardly communicate."

Another care partner whose husband's PD is quite advanced sees his loss of independence as a loss of self. Especially noticeable in how people's perception of him has changed with the progress of the disease. This same care partner when commenting on the loss of community during these later stages of Parkinson's says, “Life revolves around your immediate circle of family and friends, most of whom are saddened by your partner's decline.”

It seems the key to adapting to the various stages of your partner's PD, however unique theirs is, is to plan for it. Communicate all that you can while you still can. There is no way to accurately predict what will happen a decade from now, but some things are within your control. But when you go from a vibrant, active man of 39 to a dependent, almost bedridden one requiring 24-hour care in less than 9 years, you have no control and planning is likely impossible. That care partner is doing her best under very difficult conditions. Another story of resilience ready to be told.

# *Tips for Children and Grandkids*

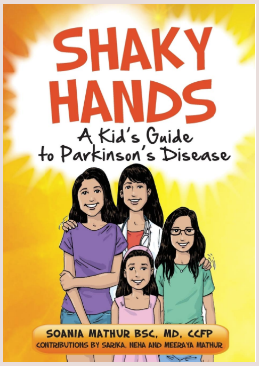
*Spouses often get all the attention when it comes to caring. But adult children and grandchildren play a very important role in supporting someone with a movement disorder as well. It's important to get educated about the disorder. The more you know the better equipped you are to help and support your loved one.*

*Supporting both parents or grandparents is especially valuable . For instance the care partner spouse will benefit tremendously from an afternoon off, even a vacation! Self care and time to unwind can make all the difference.*

*Dr. Soania Mathur and her daughters Mareeya, Sakira and Neha*

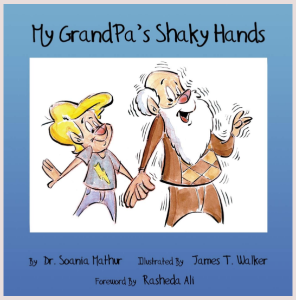
Dr. Soania Mathur was diagnosed with early onset Parkinson's. She has three courageous daughters who have never known her without it. Parkinson's is a normal part of everyday life for the Mathur family.

Read Neha Mathur's tips on how to adapt and make the challenges of having a parent with Parkinson's easier.



Shaky Hands - A Kid's Guide To Parkinson's Disease
By Dr. Soania Mathur

Parkinson's impacts the whole family unit. When a child learns that a loved one has Parkinson's disease, it can be a frightening time for them. Opening the dialogue and addressing questions like: What is Parkinson's disease? How does it feel to have Parkinson's? How is it treated? How do I deal with all the feelings I have as I see the one I love change? What can I do to help? can help children cope with a loved one's journey.



My GrandPa's Shaky Hands
By Dr. Soania Mathur

A beautiful book about a boy who can only see the positive in what others perceive as his grandfather’s disability. A grandfather who shows optimism and determination as he finds joy in life despite the challenges of Parkinson's.

*All profits derived from the sale of these books are contributed to organizations that support Parkinson’s research and programs benefitting those living with this chronic illness.*

# *Alternative Therapies*

## *Art Therapy*

Art therapy helps you explore your emotions, relieve stress, improve symptoms of anxiety and depression, and cope with a physical illness or disability.

You don't have to have any artistic talent to benefit. Art therapy usually combines the creative process and psychotherapy, facilitating self-exploration and understanding. Using imagery, colour and shape as part of this creative therapeutic process, thoughts and feelings can be expressed that would otherwise be difficult to articulate. The artwork can be used as a springboard for reawakening memories and telling stories that may reveal messages and beliefs from the unconscious mind. Creating anything new is excellent for your brain and preserves cognitive function.

Learn more about Art therapy with the Ontario Art Therapy Association and the Canadian Art Therapy Association.

Art therapists can be found in wellness centres, hospitals, senior centres and other community organizations.

Find an Art therapist using the Ontario Art Therapy Association's directory or the Canadian Art Therapy Association's directory.

CATA
Canadian Art Therapy Association
l'Association canadienne d'art-thérapie
ACAT

ONTARIO ART
THERAPY ASSOCIATION

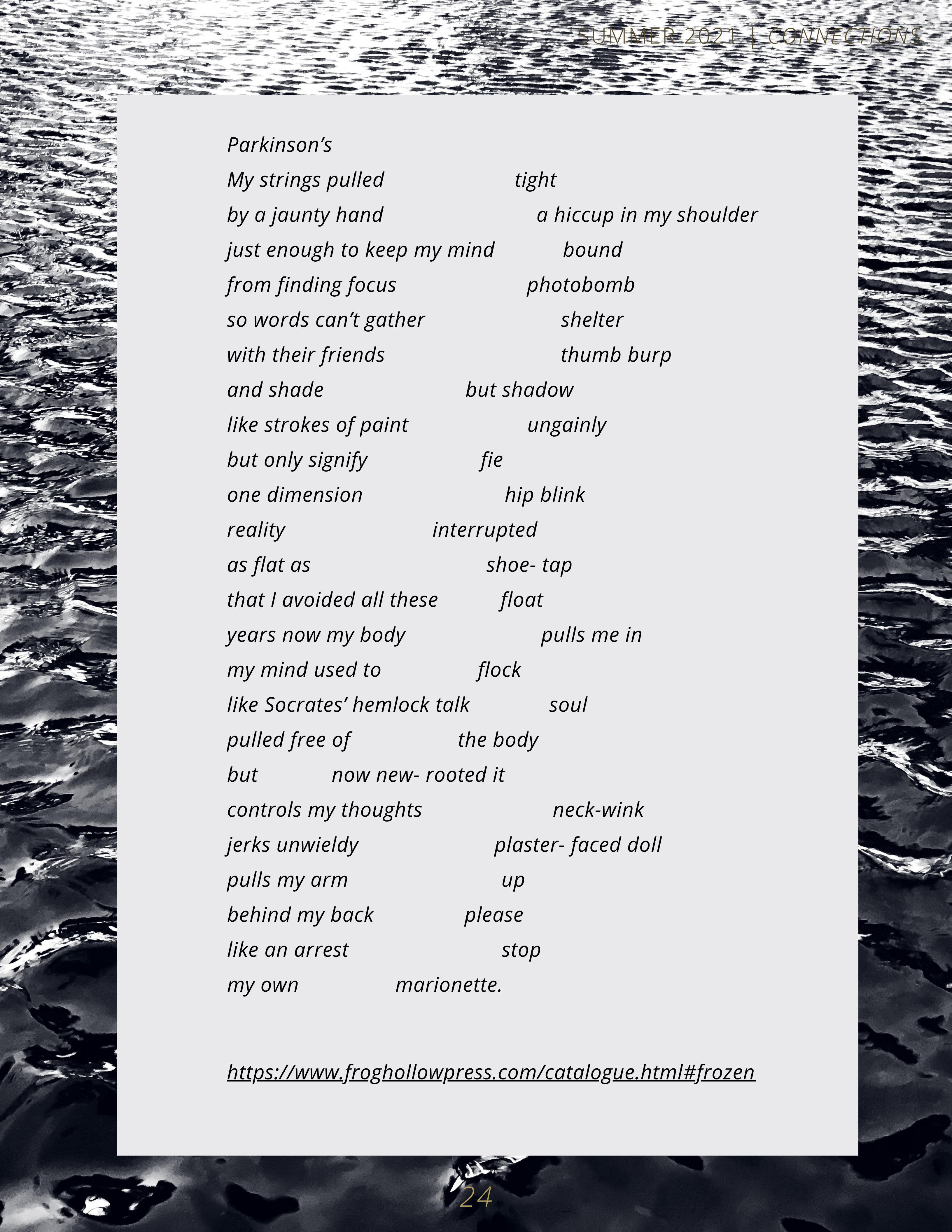
*Why not try creating art just for fun? See where it takes you! You may surprise yourself with the joy of creating! Not into painting or drawing? Try colouring books, finger painting, sculpting, even cooking can be art! Connect with your loved ones with a shared art activity and let those creative juices flow.*

*Try KiwiCo! Yes their audience is under 12yrs but so what?! Some of us have kids, grandkids, and some of us are kids at heart. Their DIY section may spark some ideas for those who don't self identify as "artists" or those looking for some doable activities and inspiration!*

# *Arts and Artists*

*So many of our patients are talented artists, photographers, writers and musicians! We are delighted to feature your creative work in this* ***new section*** *for all the artists and hobbyists out there. Share yours at movementdisorders@uhn.ca*

*Elizabeth Tessier is a Hamilton poet. Her work is informed by her 30 years working in Hamilton museums and her current life with early onset Parkinson's. She has previously published in Evenings on Paisley Avenue: Seven Hamilton Poets. She has a self-published book, The Words They Cannot Say, edited by her friend and mentor Marilyn Gear-Pilling. Her chapbook entitled Frozen Charlotte is published by Frog Hollow Press edited by Shane Neilson as part of their Dis/Ability series. She currently has work in RAVE and the Spring 2021 H&L thanks to her friend, inspiration and editor Bernadette Rule.*



### *Parkinson's*

*My strings pulled          tight*
*by a jaunty hand          a hiccup in my shoulder*
*just enough to keep my mind          bound*
*from finding focus          photobomb*
*so words can't gather          shelter*
*with their friends          thumb burp*
*and shade          but shadow*
*like strokes of paint          ungainly*
*but only signify          fie*
*one dimension          hip blink*
*reality          interrupted*
*as flat as          shoe- tap*
*that I avoided all these          float*
*years now my body          pulls me in*
*my mind used to          flock*
*like Socrates' hemlock talk          soul*
*pulled free of          the body*
*but          now new- rooted it*
*controls my thoughts          neck-wink*
*jerks unwieldy          plaster- faced doll*
*pulls my arm          up*
*behind my back          please*
*like an arrest          stop*
*my own          marionette.*

*https://www.froghollowpress.com/catalogue.html#frozen*

# *Survey results!*

*Here are a few things we learned about you from our previous surveys:*

**77%** of our readers **have a movement disorder**
**13%** are a **care partner**
**8%** are **family members**
**2%** other

**97%** of you found the newsletter **helpful, informative, and would like to see more of them!**

## Your comments:

"An enjoyable read. Also very informative and comprehensive. Really enjoyed reading people's personal stories. Thank you 😊!"

"The newsletter has a very positive, airy feeling. All sorts of resources as well. Thank you."

"The newsletter is amazing in that someone is actually looking for patient feedback. This method of reaching out will be very helpful. I have been thinking of the need for patient advocacy outreach which would really make patients more comfortable."

"Very pleased to see this new newsletter. Coming directly from the Movement Disorder Clinic is great. Not Dr. Google. Thank you, please send me all issues."

"It's very reassuring to have this resource. The clinic has provided me with answers to questions I've had for many years."

"I facilitate a Support Group and will be forwarding this to our members."

"Thank you for providing so much information and in particular the listing of so many useful resources of which I was not aware."

"The over all warmth was well communicated. Great active links and valuable information. Thank you"

"Knowledge is power!"

"Keep informing us about new trials, therapies, research and discoveries. That's one of the most motivating ways to fight PD and other diseases, to give us hope."

"Looking forward to participating in a clinical trial."

"I found the section on apathy and motivation very interesting and I will try out some of the suggestions."

"I have introduced both dance, Tai Chi and yoga into my life. Thank you."

"MDC Newsletter should be in every doctors & health office. Bravo!!"

# *Get in touch with us!*

*Thank you so much to everyone who has completed the surveys in previous issues, emailed us, provided suggestions and comments. We love hearing from you!*

**New survey!**

This is our 3rd issue and we are still learning about our readers, what you value and what you want to see here!

We have a NEW SURVEY! This one will give us a better understanding of what sections and articles you like the best.
Click here to complete our survey or email us your comments at:
**movementdisorders@uhn.ca**

We read and listen to all of your feedback! One of the suggestions you made was for more information on how caregiver's concerns are being met and what support is available for caregivers. We created this issue with that in mind.

If you made a suggestion for content and don't see it in the next issue please be patient. There are a lot of topics to cover in future issues! Feel free to send us an email.

**Share your story!**

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

Our next issue will spotlight Functional Movement Disorders. If you have a story to share, or are open to being interviewed, email us at:
**movementdisorders@uhn.ca**

*"To accept advice is to increase one's own ability"*
~ Johann Wolfgang von Goethe

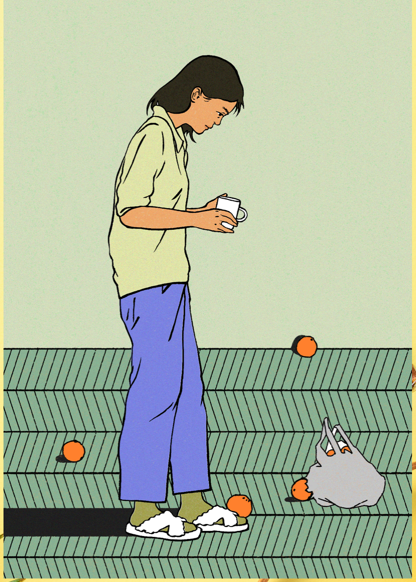
# *At your leisure*

**Double click the images to take you to the articles**

Plants can bring a lot of comfort and joy to our lives. Read about 11 benefits to having plants in your life.

If you're truly present, there will be pain, and your heart will break lots. The heart is resilient though, it can break limitlessly. Read Barry's journey learning how to offer mindful caring.

When the usual conversation starters feel stale, here's what to ask instead.



Languishing - a sense of stagnation, a joyless, aimless, emptiness, feeling blah. It may be the dominant emotion of 2021. This NY Times article explains.

# *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.

**Get in touch with us!**

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.

→ 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 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.

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.

## *Research articles*

*"Current knowledge on the evolution of care partner burden, needs, and coping in Parkinson's disease."*

- This article identified a research gap in the evolution of caregiving burden, needs and coping in caregiving for someone with Parkinson's.

*"The experience of care partners of patients with Parkinson's disease psychosis."*

- This article looks to understand how care partners of individuals with Parkinson's disease psychosis (PDP) experience their role and articulate their needs.

## *You* can help move research forward.

# *Patient Advisory Board*

Patient Advisory Board
TORONTO WESTERN HOSPITAL
MOVEMENT DISORDERS CLINIC

The Patient Advisory Board's (PAB) mission is to advise on clinical operations, research and education on behalf of persons living with movement disorders at the Toronto Western Hospital Movement Disorders Clinic, one of the worlds leading Parkinson's centres. The PAB is comprised of patients, caregivers, and faculty, allowing for collaboration between members and to foster innovation. If you are interested in becoming involved, please let your clinician know and they will pass on your contact information.

The 2nd virtual edition of the ***Movement Disorders Speaker Series*** was held on April 14th.

This time around the focus was on ***Making Patients Partners*** - showcasing the Patient Advisory Board (PAB)! Their impact on patients with movement disorders, what they are striving to achieve, and how you can help and support this group to fulfill their mission.

*Making Patients Partners - April 14th 2021*

The 1st virtual Speaker Series

*Multidisciplinary Care for Parkinson's disease: Building a New Program with Patients as Partners - Sept 30th 2020*

Follow us on Facebook to stay up to date on events and what we are up to!

# COVID *Resources*

*In the third wave, we seem to be at a standstill, awaiting to be fully vaccinated and anticipating a return to a new normal life. We are all tired of COVID, but we can find solace in knowing we are all, and have all, been in this together. Stay informed.*

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 Toronto vaccine information, news, and information on restrictions and public measures to keep you safe.

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

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.

Check out Press Reader for online access to newspapers and magazines from over 100 countries in over 60 languages!

Various articles written with helpful information during these difficult times. Attending a funeral, supporting a bereaved person during self isolation, talking to children about the pandemic and practical tips to get through.

# You are not alone.

Part of self-care is reaching out when you need to.

The Ontario Caregiver Helpline will connect you with resources and support, 24 hours a day, seven days a week.
**Caregiver Helpline: 1 833 416 227**
A live chat is also available Monday to Friday, 9 am. to 7 pm. ontariocaregiver.ca

Looking for more resources and information on movement disorders?
Check our past editions of *MDC Connections*.
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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