

Welcomed by President Wayne, everyone was greeted individually. People seemed to log on one at a time which made it nice for greeting and making introductions as we went along.



We extend our sympathy to the family of Aline Leveille-Mallet, who passed away Nov. 13, 2021. Aline was a fairly recent addition to our group and was in fact one of our “virtual” members, attending by reading our meeting notes and sharing the occasional phone call and benefiting from the educational materials sent to her.

<https://www.sudbury.com/obituaries/leveille-mallet-aline-4753181>

Introductions: There were 17 in attendance, some local and some from as far away as Timmins, Blind River, and near Sturgeon Falls. Each person was asked to introduce themselves and tell how long they have been diagnosed and what is their most annoying symptom. We even managed to share a few “small world” connections.

Announcements:

- Parkinson Canada are revisiting their in-person meeting policy and examining the vaccination status policy. They are looking at re-opening, with proof of vaccination, the end of January. We will be learning more about this at a meeting next week.
- **Wheelchair**, in almost-new condition, offered to anyone in the Parkie group who could use one. Comes with a gel cushion to help prevent skin breakdown. If you are interested or even know of someone in need, please contact Nora Lea and she will put you in touch with the donor.
- **Books available to borrow:**
 - ***Lucky Man by Michael J. Fox***, about his early years living with PD.
 - ***Always Looking Up; the Adventures of an Incurable Optimist, by Michael J. Fox***, stories from his middle years with PD.
 - ***No Time Like the Future: An Optimist Considers Mortality, by Michael J. Fox***, stories from his most recent years with PD. (There was an interview on CBC's “Q” with Tom Power this week, Louise said it was very well-done. <https://www.cbc.ca/listen/live-radio/1-50-q/clip/15877804-full-episode-michael-j.-fox-doug-knutson-cynthia>)
 - ***Alex Trebek, The Answer Is . . . Reflections on my Life***; a very positive read, easy and light short stories, No, he didn't have Parkinson's, its offered just because he was a Sudbury boy.
 - ***Every Victory Counts*** from the Davis Phinney Foundation. A strongly uplifting book full of stories and information. You will find encouragement to celebrate every victory, even the little ones, it is a book you will refer to many times. There is a Canadian version coming out in January, in collaboration with Parkinson Canada. You can put your name in now for a free copy. In the meantime, you can borrow ours. Apply here: <https://www.parkinson.ca/gated/every-victory-counts/>

The following are some educational sites that offer a lot of information on Parkinson's. Please don't feel pressured to watch any of these. They are offered as a source of information and a place to look when you have questions. Just pick and choose what catches your interest.

Recent Webinar from World Parkinson Congress: The Emotional and Social Impacts of Motor Complications in Parkinson's Disease Louise says this is one of the best webinars she has ever attended (and that is quite a few!) The archive was just made available. You have to register and then view (you get the link right away). <https://event.netbriefings.com/event/wpc/Archives/motor1121/register.html>

Upcoming Webinars:

Skin & Bone Health Wednesday, December 1, 2021, 1 to 2 pm.

As Parkinson's Disease progresses, it is common to experience changes in skin and bone health. Weakened skeletal and bone health can increase risk of falls and balance issues. Changes in the skin or trouble with excessive sweating are also common symptoms of PD. Recent studies have shown an increased prevalence of skin cancer among people with PD. Learn about these changes and how to address them.

https://secure3.convio.net/prkorg/site/Calendar?id=107851&view=RSVP&_ga=2.197796263.928889186.1637167195-604490623.1632338595 If you attend and wish to make a few comments about this one at the next meeting, it will be appreciated.

Emerging Therapies: Focussed Ultrasound and Stem Cell Therapies Wed. Nov. 24, 2:00 - 3:00 pm

https://parkinsoncanada.zoom.us/webinar/register/WN_GhCFsQBcRAK7sLSU0tH7kA

Joanne McN has signed up to attend this one and will report her impressions to the group.

For those of you interested in knowing what research is going on, the Michael J. Fox Foundation is having a Webinar on Thurs. Nov. 18. **"Steps Closer to Stopping Parkinson's: 2021 Research Review"**. If you register for the session, even though it has passed, they will send you the link for the recorded version which can be played immediately.

Exercise Break: Lillian led us in a short exercise session, to get us warmed up and the blood stirring again. Loosening up the muscles helps us be more comfortable in the next discussion.



Don't forget the **Parkinson Mobility Program** offered at the Parkside Centre on Mondays and Thursdays (Natalie at 705-673-6227, ext 231). Also **Rock Steady Boxing** is back – talk to the folks at Top Glove Academy (Call Gord at 705-561-7215).

Today's Discussion Topic: National Family Caregivers Month

November is National Family Care-Givers Month and we have chosen to focus on communication between PWP (people with Parkinson's) and their care-partner as our discussion topic.

Choosing from a selection of statements on slides presented at a fairly recent Webinar by Dr. Angela Roberts at Northwestern University (Chicago), Wayne introduced the topic and led the discussion.

Causes of Conversation Breakdowns in PD Dyads (pairs /couples)

66% of breakdowns are unrelated to speech clarity and voice loudness issues, although as our discussion revealed they do have an impact! Along with hearing difficulties (on the part of our care-partner, of course 😊), other factors had a significant impact as well: noisy environment, internal states (pain, distraction, impatience), rushing or being in a hurry, and poor attention, to name a few.

Changing topics quickly or starting in the middle of a thought or idea can make it difficult for the other person in the conversation to follow. Possibly due to slow processing of information. If the topic is unclear or not consistent with the current context it can confuse the conversation. So does talking over or interrupting the person with PD.

You can imagine the stories that came out as Wayne touched on these various topics. There was lots of laughter as different ones recounted experiences of failed or missed communication due to a variety of Parkinson's symptoms.

Some suggestions to facilitate communication:

Minimize Environment Distractions

- Turn off televisions, radios, running water and other sources of noise (visual and auditory)
- Reduce barriers by communicating face-to-face
 - Resist talking between rooms
 - Resist talking while walking away
- Provide alerting cues (especially if you are going to change the subject!)

Provide Additional Time

- Provide time to process information and to formulate responses
- Present information in smaller 'chunks'
- Listen patiently
- Avoid rushing or having important conversations during hurried moments



A few suggestions from the group:

One fellow asks his care-partner to be his “coach” and help to keep him on track (particularly while he is on the phone).

Another member asks for visual cues to remind them to speak up (like the care-partner cupping his hand behind his ear).

One said she knew if she thought she was yelling she was probably speaking loudly enough to be heard. (That led to a whole different topic of discussion, and more laughter as people recounted tales of yelling out during their sleep with perfectly clear enunciation.)

Another idea that helped one fellow, is making a list prior to starting a telephone conversation.

Meaningful and effective conversation require flexibility, empathy, and the ability to adjust over time.

The payoff in preserving sense of self, emotional connections, and reducing the burden of daily activities is worth it.

To wind up the meeting on a positive note, we posed a question from Wayne, “Where do you find the joy in life?” One of the responses that led to more stories and laughter, Joanne McN said she had discovered a new source of joy while engaging in another. Out hiking one day she had picked up a stick to use as a gait-stabilizer while walking on uneven ground. After the walk she looked at the stick a little more closely and decided to clean it up, sand it a little, apply some finish, add a rubber tip for summer and an ice-pick for winter, and presto! A new hobby was born!

The meeting closed promptly at 3:30 pm. Comments: “It was a relief to know I am not alone.” And another, “I appreciate the laughter and the sense of humour evident in the group. It helps.”

Next Meeting: Christmas Gathering (via Zoom) Wednesday, Dec. 15 pm at 2 pm

Anyone wish to volunteer to help plan and deliver this as an online party?

Call Nora Lea Arcand, Secretary, 705-522-3321 or cell 705-918-3323

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