

Welcome – Wayne & Nora Lea welcomed people as they joined the Zoom chat.

Wayne reminded us that the photo book is now available for borrowing. So far those who have looked at it have enjoyed it and found it fun, memory-stirring and very heartwarming.

Memories – The Parkinson’s Support Group of Sudbury 20 years of Living Well – Together

A Photo History of the past 20 years of the group, documenting all the fun we’ve had together. PDF copy can be downloaded to your computer, you can borrow a copy as you would from a library, or you can buy one. When Louise & Richard get back from their trip to the Azores, they can order “hard copies”. Their experience is that the company offers sale prices several times a year, but with a very short window of time to get an order in. It will be most advantageous pricewise if we have an order ready to go in mid-May and are willing to wait for the next good sale (even with the sale price, it comes to about \$100 each). To borrow a copy or to place an order, or to arrange for the book to be downloaded to your computer call or email Nora Lea.

In Memory:



⇨ Dwight Brady passed away on March 21, 2022. You may remember him from his faithfulness at exercise classes and the Superwalk until he moved down south to be closer to family.

⇨ John Bernier passed away March 24, 2022. John lived at the Southwind and would attend meetings with his daughter, Michelle Bernier-Wilson. Sitting in the back of the room he could see

everything and take it all in, responding with a smile and a merry twinkle in his eye, and he often had some pithy comment to make.



Our sympathies also to Marc & Anne Pelland and the family on the loss of Marc’s father recently, He was 91. <https://www.sudbury.com/obituaries/pelland-claude-5229439>

News

On a more cheerful note, we were delighted to have Alex & Gord from Top Glove Boxing join us for a presentation of the Rock Steady Boxing program.

Alex Webster, Indigenous Liaison with Top Glove Boxing Academy and Gord Apolloni, Head Coach and owner at Top Glove Boxing Academy

Gord talked about the benefits people who participated in the program had experienced, including reduced dependence on canes and/or walkers, reduced tremor, increase in energy and improvement in mood. Brian and JoAnne participate in the program and they were strongly positive in their assessment of its effectiveness.

- The program is offered Tuesdays & Thursdays from 10 – 11:00 am
- People with Parkinson’s are encouraged to bring a “corner person” to work out with them, at no additional cost
- They will teach your corner person how to support you, and how to get you up if you fall (something we all should know!).
- The cost, taxes in, comes to about \$90/month

- Call ahead if you want to schedule a visit to observe the program in action.

There is a poster attached to the email with more details, and a [link here](#) to a number of articles showing how forced exercise helps improve motor functions in Parkinson's patients.

A serendipitous moment: when one of the boxers realized he knew the husband of one of the attendees – they had boxed together years ago. We got to watch the reunion, and hear as they planned to reconnect. Neat!

More exciting news

(drum-roll please!)

Brian introduced the new website for the Sudbury support group: <https://parkinsonsudbury.ca>. This replaces the one we had previously that expired and was bought by some Japanese company, who tried to sell the domain name back to us. Since that one had such a tricky name, we opted to just rebuild a more user-friendly site, that could be maintained easily by at least a couple of members of the group. For this one, we tried to choose a name that would be short and sweet and not too prone to error, as well as one that would show up quickly on most searches.

Wayne was fervent in his praise for what Brian has accomplished in building this site, and compiling information from various sources to make it useful and informative. He finds it easy to navigate and commented that it is much cleaner and more straightforward than many professionally built sites. Many, many thanks to Brian for his work on this!

If you find errors or omissions, please let Brian know (info@parkinsonsudbury.ca). There are a few pictures we already know we want to change to ones that are more current, just haven't had the time to search for them yet. Any suggestions for improvement will be gratefully considered. (Such as linking it to our Facebook page, a suggestion from Brian himself.)

Exercise Break

Time to practice what we preach and get moving! Lillian led the group in a few blood-stirring exercises. "Motion is Lotion"! Thanks, Lillian!

Superwalk

Parkinson Canada will be launching its 2022 Superwalk website on May 10th. You will be able to access the site and build your own profile page, so your supporters can find and direct their donations to your credit. People seem to love this way of giving – they get your email request for sponsorship, a few minutes and a couple of clicks later, they have made their donation and received their tax receipt.



Wayne informed us that **Richard Carriere and Claire Sheridan** will continue as co-coordinators. This annual fundraiser will be happening on Saturday, Sept. 10, 2022 at Delki Dozzi Park. As an outdoor event, it will be an excellent way to ease back into in-person gatherings. In the meantime, we can start collecting pledges from the family and friends we may see during the summer. Claire shared that one of the charities that usually has a table at the Walk, UCT/ACT, has already committed to make a donation to our local group.

Tricks & Tips for Activities of Daily Living:

Since our OT was not able to be here today, we thought the group could share some ideas of what works or has worked for us. That is why I asked you to bring yours to the meeting.

Basically a “show and tell” of suggestions of ways to improve our independence at home and promote safety.

We’ve all heard the trick to try when turning over in bed is an issue, how wearing satin pyjamas or using satin sheets can make that much easier. But not both at the same time, as one friend found out to her chagrin, picking herself up from the floor.

There are many techniques and assistive devices that can help us, whether we are people with Parkinson's or have other limitations, or simply are dealing with the realities of aging. An OT (Occupational Therapist) can assess our situation and help us determine what devices would help us the most.

- Things like canes and walkers and scooters, we see people using all the time.
- Partial bedrails to help with getting in and out of bed,
- raised toilet seats or “handle bars” to assist with getting up and down off the facilities are a real boon.
- Grab bars in the shower or bathtub, handles that go on the side of the tub, encourage independence in these ADLs as they increase safety and a sense of security.

These are all things that any number of people can benefit from. However, there are also things specific to Parkinson’s that can be helpful that are less well-known.

If freezing of gait (FOG) is an issue, (this is when you get stuck, and your feet feel frozen to the ground. It may happen when approaching a doorway or narrow space, or navigating corners.)

- a laser beam on a walker can be a real boon, as it cues us to step over it; or
- a laser pointer you can use as a “flashlight” marking the spot for you to step over
- a flip-down piece on a cane that encourages a “step-over” action.
- Learning about verbal cues, such as
 - counting out loud,
 - walking to the beat of a metronome, or
 - playing music on a Walkman or I-pod or your cellphone (depends what generation you’re from),
- focussing on each part of your step can also help “lift, down, heel, toe; lift, down, heel, toe,” etc. or something as basic as “left, right; left, right; left, right,” “Hup, 2, 3, 4; Hup, 2, 3, 4.) As you do this under your breath, people may give you a funny look. Just tell them you are talking to your feet! 😊

These are just a part of a list of ideas that can help with freezing. It is attached to the email.

For hand tremors, ideas like we heard about last month such as

- the Steadiwear glove are being developed, also
- weighted cutlery along with other items that help for a while.
- Little ditties that bring a smile are also a bit of a stimulus to be conscious of what we are doing, “Big cup, half-full; good drink, no spill”.
- JoAnne showed us one trick she discovered with her salt and pepper shakers: turn one upside down and then set the other one on top and twist. The little bumps on the bottom are designed to cause a vibration and out comes the pepper or salt.
- Someone suggested drinking soup from a cup rather than trying to spoon it from a bowl (without spilling), and then using two hands to hold the cup.

Handwriting issues (micrographia)

There doesn't seem to be a magic cure, some suggestions were: patience, relax and take your time. Wayne recalled the handwriting study we were involved in with Dr. Penny MacDonald where we spent an hour a day copying excerpts of famous literature onto foolscap pages. I'm not sure what exactly they learned from the study, but we learned practice, practice, practice pays off!

<https://parkinsonsdisease.net/symptoms/micrographia-handwriting>

Trouble holding your phone for a Face-time call? Wayne showed us a small tripod he was given for Christmas (it came with a selfie-stick that has a remote). It works to hold the phone while you enjoy a hands-free call. Then he reminded me of the holders we had made out of toilet paper rolls. Ours were papered and decoupaged, at Easter (can you tell?) the first year of Covid. Here are a couple of how-to videos, each a different style:

- <https://www.youtube.com/watch?v=QD9PiqFPtNo>
- <https://www.youtube.com/watch?v=sco6M9O-iZg>



Balance Issues: Someone was asking about the walking poles that people are gravitating to. They are certainly beneficial in maintaining your balance, and with the different tips they can be made suitable for all types of weather.

Nordic Pole Walking is demonstrated here: <https://www.youtube.com/watch?v=8RrxSloH2Qs>

Urban Poling is another type we are familiar with: <https://urbanpoling.com/> If you scroll down on this site there is a section specifically for Parkinson's.

Do you forget to take your pills? Claire showed us the ultimate pill-reminder especially for people with Parkinson's Disease. Click [Reminder Dosette](#) to see the amazing Tab Time Super 8, Electronic Pill Timer-Reminder-Dispenser, with up to 8 audio and visual alarms per day. There are features designed especially for PWP, such as it will keep ringing until the case is opened or a flashing light will show. Alarms can be easily set for the same time each day. She said Chris has found it handy. He puts it in his pocket before leaving the house in the morning and he has his pills for the day, ready to go, even if he is gone longer than originally planned.

Nora Lea pours her pills for a week at a time in dosettes that are marked for Parkie Pills (one set) and other meds (in another set) then lashes the two together with an elastic band. Then she sets the alarms on her cell phone for the various times throughout the day. Specific instructions that came with the medication can be added to the alarm label (ie: "take on an empty stomach with a full glass of water", or "take with food"). The pills and the phone go with her wherever she goes over the course of the day.

Wrapping up with some general chatting and the meeting ended just before 3:30 pm.

Next Meeting: Wednesday, May 18th at 2:00 pm via ZOOM. (Sorry, not in person yet!)

