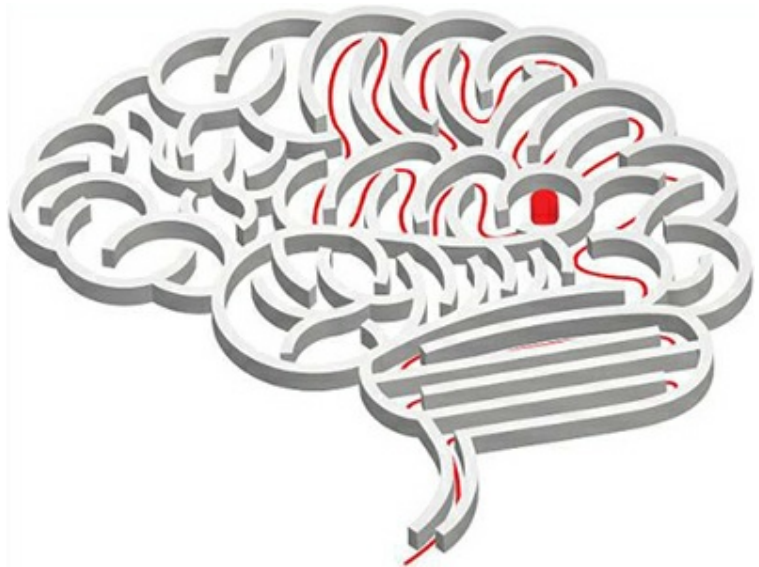


eParkinsonPost – An online publication of Parkinson Canada for Canadians living with Parkinson's disease

 parkinsonpost.com/

This April, we are heading into communities near you, to raise awareness and share information about living well with Parkinson's disease. We invite people living with Parkinson's, care partners, and health care professionals to join us in spreading the word.



4-6 April 2018 – Vancouver, BC

Parkinson Canada joins The Parkinson's Foundation and the Movement Disorders Society in Vancouver, BC at the *Allied Team Training for Parkinson's™ (ATTP)* for health professionals. Find out more [online](#).

7 April 2018 – Winnipeg, MB

Join Parkinson Canada and other Parkinson organizations at the *Davis Phinney Victory Summit®* in Winnipeg. [Advance registration online](#).

10 April 2018 – Dorval, QC

Join Parkinson Canada and The Cummings Centre for an afternoon of learning about *The Parkinson's Bladder and Bowel*, with experts on the subject – Dr. Lysanne Campeau, Urologist and Dominique Longpré, Dietician. \$10 at the door with advanced registration required at infoQc@parkinson.ca or 514-734-1819.

11 April 2018 – World Parkinson Day

Happy Birthday to Dr. James Parkinson. Follow us on Facebook and Twitter. Together, we will #UniteforParkinson's. Help spread the word online.

24 April 2018– Ottawa, ON

Parkinson Canada is heading to Parliament Hill. Want to be a Parkinson's Ambassador? [Find out more](#) and register online today.

26 April 2018 – Lanark North Leeds, ON

Parkinson's Education Event: Two sessions per location – session will be broadcast to selected Ontario Telemedicine Network (OTN) sites. General public session begins at

10:00am. Health professional session begins at noon. [Register online today](#) as seating is limited.

27-28 April 2018 – Saskatoon, SK

Inspired Movement – our 2018 Education Conference in Saskatoon, featuring dance, exercise, and yoga is designed to get you moving and keep you moving. Find out more and [register online today](#).

And don't forget to support *Hope In Bloom* tulip campaigns in your community, or send a virtual greeting at: <http://donate.parkinson.ca/april>.

Our mission is to transform the lives of People Living with Parkinson's. We do this through: research leading to the end of Parkinson's; advocacy bringing the voices of Parkinson's to the forefront; support helping people living with Parkinson's live well through programs and education.



...A care partner feels powerless to help her spouse when he makes no effort to try treatments other than medication, like exercising or joining a support group, to help them both live better with Parkinson's.

...A person living with Parkinson's is mortified when someone in their local community thinks they are intoxicated when they encounter them in a store. They subsequently refuse to go out, except to medical appointments.

...Another care partner wants to know how to create a "safe space" to communicate with his partner living with Parkinson's.

These are some of the complicated situations that were addressed during a Parkinson Canada webinar, entitled: ***Coping with Parkinson's: Strategies for the Person with Parkinson's Disease, the Care Partner and Health Professionals***. You can replay the November 2017 webinar anytime [here](#).

Social worker and expert presenter Elaine Book offers specific approaches, conveyed with knowledge and compassion, to help anyone coping with the challenges of living with Parkinson's disease. Working at the Pacific Parkinson's Research Centre, her presentation

contains plenty of real-life examples, similar to the situations noted above.

She begins the webinar describing the feelings that must be recognized and acknowledged by people living with Parkinson's and their families. You need to understand that you are experiencing changes in every aspect of your life, beyond the physical symptoms of Parkinson's disease, such as changing family roles, routines, work, financial circumstances, intimacy, and facing an unknown future. The resulting feelings can include shock, fear, anxiety, grief, guilt, shame, anger, and stress.

"As a patient once told me, 'my place in the world is changing' and it is important to attend to any unaddressed feelings of loss, grief, anger, stress, and depression," says Book. "How you manage these feelings does have an impact on managing your symptoms and your life with Parkinson's."

Grief usually accompanies loss. "Grieving can be a good process," says Book. A period of grief is normal and is characterized by good days and bad days.

Depression is more consistently a negative experience. Up to 50 per cent of those with Parkinson's experience depression, whether it is a neurological symptom of the disease or a result of living with Parkinson's. "It is often a combination of the two," says Book. "The good news is that anti-depression medication can be effective in helping you get through a critical period. The sooner depression is addressed, the better, because we know that it also has an impact on the physical aspects of the disease."

A feeling of shame or stigma is often related to the visible physical symptoms of Parkinson's such as tremors, an awkward gait, a facial "mask" and slurred or soft speech. Strangers may assume the individual is intoxicated or intellectually challenged. A common reaction is to hide from embarrassment or humiliation, resulting in social isolation.

Book advocates that you continue to do the activities that define you and "dare to share" your diagnosis and educate others about your condition. "Most people will respond positively, perhaps with some questions, as well as offers of assistance," says Book. "This is your opportunity to raise awareness and that can be empowering, not shameful."

Stress can also impact physical health. It is the body's reaction to a change that requires a physical, mental or emotional adjustment in response. It is important to be aware of stress and what is causing it, so that it can be addressed. Individuals with Parkinson's need more than just awareness about being stressed. They need to find the cause and make adjustments to alleviate it.

"Parkinson's disease requires a continuous need to cope with the stresses of living with a chronic disease," says Book.

She also urges health professionals to identify the "invisible" symptoms of living with Parkinson's and to be aware of the perceived shame and stresses in people living with Parkinson's disease. A holistic assessment can help identify challenges so that they can be addressed in order to improve the quality of life for all of those affected by Parkinson's

disease.

Book describes different types of coping strategies, including:

- **Task-oriented:** analyzing the issue or challenge and taking action to solve it.
- **Emotion-oriented:** attending to your feelings through counselling, a support group, friends and family, or on your own with meditation, yoga, etc.
- **Distraction-oriented:** engaging in activities, such as exercise, hobbies or volunteering.

Most people make use of all three types of coping strategies. A list of coping strategies and tips is found [here](#), under the heading *Manage your Parkinson's*. Book also encourages individuals to focus on their strengths and how they got through challenges in the past. "Write them down," she says. The handouts include a "strength word list" to get you started.

The presentation also addresses "life hacks," small things you can do that make life easier, like using liquid soap in the shower instead of bar soap, so you don't need to worry about grasping it, or using a stand for you mobile phone, so you don't need to hold on to it when using it, or using bowls with a silicone base, so they don't slide around on the counter or table.

There is no right or wrong way to cope with Parkinson's. Each individual's journey with the disease is different and so will be the ways of coping with its challenges. Book asks people living with Parkinson's and their care partners to remember that "asking for help is not a sign of weakness, rather it is a sign of strength."

Book also shares a story illustrating the importance of a positive attitude... A woman wakes up and finds she has three hairs on her head, so she decides to fix her hair in a braid and enjoys a wonderful day. The next morning she wakes to find she has two hairs on her head, so she decides to part them in the middle and goes on to have a fulfilling day. The next morning, she wakes to find just one hair on her head, so she goes with a ponytail and has a lovely day. The next day she wakes to find she has no hair left at all. "Great," she says, "I don't have to fix my hair," and she gets on with her life. Positive attitude goes a long way.

Book encourages people with Parkinson's to simplify and streamline their lives and to change their expectations. As one individual with Parkinson's told her, "Parkinson's has not changed the course of my life, but rather it is now a part of the course of my life."

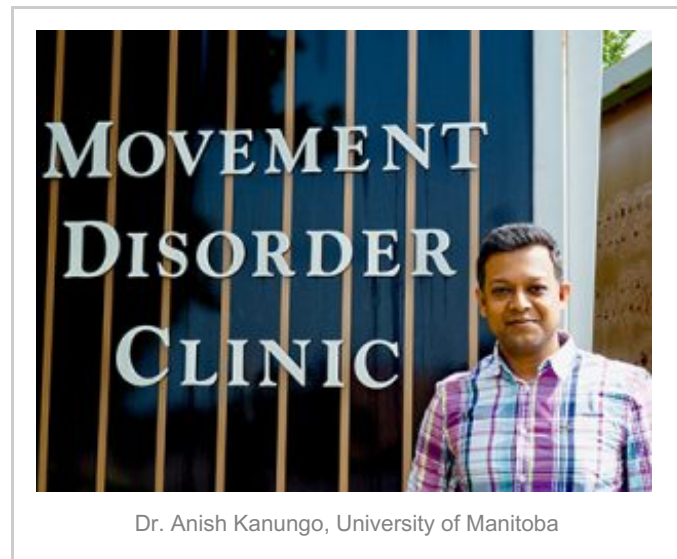
At the close of the webinar, other resources are offered to help cope with Parkinson's, including websites, books and fact sheets. Parkinson Canada offers a series of webinars on its [YouTube channel](#) along with a calendar of upcoming podcasts and webinars which can be found [here](#).

Visit www.parkinson.ca for a wealth of information and resources to help people live well with Parkinson's.

Know that you are not alone. Parkinson Canada staff and volunteers are ready to help. Call our Information and Referral Helpline at 1-800-565-3000 or email your questions to info@parkinson.ca.

At the University of Manitoba, Dr. Anish Kanungo is attempting to change the minds of legislators who have been reluctant to use public dollars to finance dedicated clinics for the care of people with Parkinson's disease.

"The hard thing is that we don't have a cure for this disease ... but symptom management and quality of life – that's an important goal," says Kanungo, a neurologist who is spending a year as a clinical movement disorders fellow.



Maintaining a good quality-of-life in people with Parkinson's disease has moved beyond simply prescribing levodopa. Today, caring for these patients requires experienced neurologists with specialized training in movement disorders who are knowledgeable about the explosion of growth in therapies available now and in the near future.

"There are a lot of approaches to the treatment of Parkinson's disease that you don't master in five years of neurology training," Kanungo says. "You need the extra year of fellowship to develop the competency needed to manage the subtle aspects of the disease."

In addition to treating patients, Kanungo is also analyzing Manitoba's population health database to compare outcomes for people with Parkinson's who are being treated at the clinic, to outcomes of people with Parkinson's being treated by family doctors and general neurologists in the community.

"Having (specialized care) on one site and under one banner is, we think, the most efficient way to do this – but nobody has really evaluated it," he says. "As a result, there has been a reluctance to publically fund such clinics, despite the growing population of patients with Parkinson's across Canada."

Although such clinics have been established in Centres of Excellence, waiting lists are extensive. Frequently, patients with Parkinson's must travel great distances from their home communities to reach such centres. That's why Kanungo hopes to practice in a smaller community outside Manitoba when he finishes his fellowship at the Movement Disorder Clinic at Winnipeg's Deer Lodge Centre.

While undertaking his fellowship, funded by Parkinson Society British Columbia through the Parkinson Canada Research Program, Kanungo will be uniquely situated to perform this analysis.

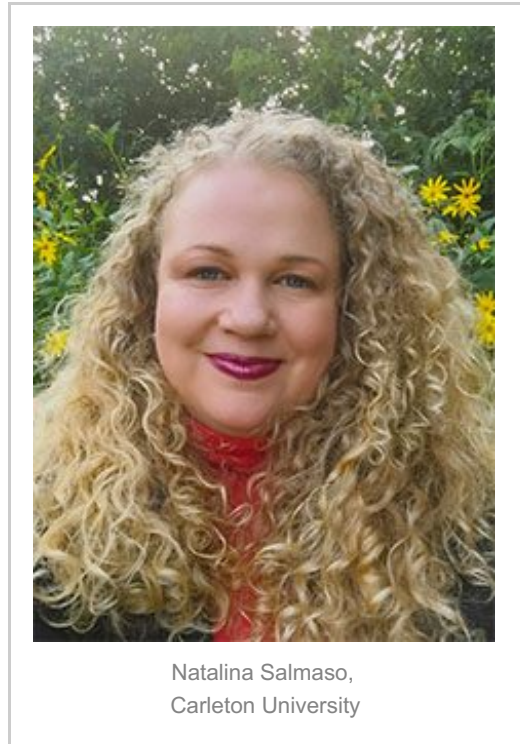
“Having only one such clinic in Manitoba allows for a more direct comparison of health outcomes and costs between these models of health provision in Parkinson’s disease – as opposed to other regions, where two or more movement disorder clinics have been established.”

Read about other researchers recently funded by the Parkinson Canada Research Program by visiting the research section of www.parkinson.ca.

About half of the human brain is made up of cells, known as astrocytes, which researchers used to think were like the scaffolding that holds the more important neurons together.

But Natalina Salmaso knows better. She calls astrocytes the underdogs of the brain: a dynamic class of cells that are just as busy as neurons, but whose work historically went unrecognized. Her research involves revealing how these cells help our brains stay at their best.

Salmaso, who holds the Canada Research Chair in Behavioural Neurobiology at Carleton University, has spent much of her career studying astrocytes, although not in the context of Parkinson’s disease. She was intrigued when she learned that a lot of the research on this disorder had dealt with astrocytes.



“Astrocytes go to the neurons when they are dying,” she says. “When this happens in Parkinson’s disease, the astrocytes are gathering around them, they’re changing their shape, and they’re emitting different biochemical factors. People have noted these changes are occurring, but no one has really investigated what it means.”

Now, having received a one-year Pedaling for Parkinson’s Pilot Project Grant through the Parkinson Canada Research Program, Salmaso is going to stimulate astrocytes to learn how they confront the impact that Parkinson’s has on neurons. To do that, she’ll use a virus that has been genetically modified to be sensitive to light, which will interact with astrocytes in a controlled fashion.

“The idea is to understand what the stimulation does,” she says. “We believe the astrocytes are trying to heal the neurons, but failing for some reason. At a molecular level, we want to target what they need to do to heal those neurons earlier in the game.”

Salmaso believes that targeting astrocytes is akin to using probiotics, which enhance the body’s innate capacity to stay healthy. In the case of Parkinson’s, astrocytes may be trying to do the same. But Salmaso thinks they’re overwhelmed by the amount of inflammation and cell

death that has already occurred in the brain. If she can prove that theory, it will set researchers on a path to discovering other mechanisms to help the astrocytes succeed at their job.

“The more we understand about how these cells do their job to keep neurons healthy, the more we can mimic that in any model of disease.”

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We are pleased to inform you that apomorphine (MOVAPO) has received a positive recommendation by CADTH, the Canadian Agency for Drugs and Technologies in Health. Parkinson Canada filed a patient evidence submission for the review process that was informed by a survey from nearly 900 people with Parkinson’s and caregivers, as well as interviews with individuals using apomorphine in Europe. Here’s the full recommendation report from CADTH:

https://cadth.ca/sites/default/files/cdr/complete/SR0527_Movapo_complete-Jan-25-18.pdf

A positive recommendation means CADTH is recommending that the provinces offer public coverage for the cost of the drug for patients (with conditions):

APOMORPHINE HYDROCHLORIDE (MOVAPO — PALADIN LABS INC.)

Indication: Parkinson’s disease

RECOMMENDATION:

The CADTH Canadian Drug Expert Committee (CDEC) recommends that apomorphine hydrochloride (apomorphine) be reimbursed for the acute, intermittent treatment of hypomobility “off” episodes (“end-of-dose wearing off” and unpredictable “on/off” episodes) in patients with advanced Parkinson’s disease (PD), if the following criterion and conditions are met:

Criterion:

- Apomorphine should only be used as adjunctive therapy in patients who are receiving

optimized PD therapy (levodopa and derivatives and dopaminergic agonists) and still experiencing “off” episodes.

Conditions:

- Patients treated with apomorphine should be under the care of a physician with experience in the diagnosis and management of PD.
- Reduction in price.

This is a positive and necessary step to getting equitable access to the drug for people with Parkinson’s who would benefit from it; however, this is the beginning of the process.

Please don’t make any changes to your therapeutic regimen without discussing this first with a health professional. Remember that your doctor or pharmacist can help you manage your medications.

Parkinson Canada will continue to monitor the availability of apomorphine and will share updates as they become available. If you have any questions about this process or other matters concerning the Parkinson’s community, contact Parkinson Canada’s advocacy team at (800) 565-3000, ext. 3501 or email advocacy@parkinson.ca.