

VIEWPOINTS



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SUMMER 2019

A QUARTERLY NEWSLETTER
BY PARKINSON SOCIETY
BRITISH COLUMBIA

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THE BENEFITS
OF SINGING FOR
PEOPLE WITH PD

Suite 600 - 890 West Pender Street, Vancouver, BC V6C 1J9
Phone 604-662-3240 | **Toll Free** 1-800-668-3330 | **Fax** 604-687-1327
Charitable Registration Number: 11880 1240 RR0001
www.parkinson.bc.ca | info@parkinson.bc.ca

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OUR MISSION

Parkinson Society British Columbia exists to empower people with Parkinson's in British Columbia through providing resources and services to enable self-management, self-reliance, and self-advocacy.

YOUR SUPPORT IS ESSENTIAL

Parkinson Society BC would not exist without the support of our members, donors, and volunteers. Here are a few of the ways you can support your Society:

Membership: For an annual fee of \$25, your household benefits from unlimited access to our education and support services, events, and resources.

Donations: Contact us to set up monthly, quarterly or annual donations, or think of us when giving through United Way.

Special Events: Ticket sales from our educational and fundraising events support the Society's programs and services.

Planned Giving & Bequests: Consider Parkinson Society BC as a beneficiary in your will.

Fundraising: Become a Champion for Parkinson's by organizing your own event benefitting the Society.

For more information on how you can support us, visit www.parkinson.bc.ca/donate.

SUPPORT GROUPS

Our network of over 50 volunteer-led support groups provide people with Parkinson's, and their caregivers and families, an opportunity to meet in a friendly, supportive setting. For our full support group listings, visit www.parkinson.bc.ca/groups.

100 Mile House, Abbotsford, Burnaby, Campbell River, Carepartner Online, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, Cranbrook, Duncan/Cowichan Valley, Fort St. John, Kamloops, Kelowna, Kelowna Carepartners, Kelowna West, Kootenay Lake East Shore, Langley, Langley YOPD, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Nanaimo, Nanaimo Carepartners, Nelson, New Diagnosis Online, New Diagnosis (Vancouver), New Westminster, North Shore, Osoyoos/Oliver, Parksville/Qualicum, Parksville/Qualicum Caregivers, Penticton, Port Alberni, Powell River, Prince George, Quadra Island, Quesnel, Richmond, Richmond Carepartners, Shuswap/Salmon Arm, Sunshine Coast (Sechelt), Surrey, Terrace, Trail/Castlegar, Tri Cities, Tri Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Carepartners, Vancouver Downtown Working Professionals, Vancouver West Side, Vernon, West Vancouver Carepartners, White Rock, White Rock Carepartners, YOPD Online

EDITORIAL STATEMENT

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RESEARCH

Topographical Analysis of the Trajectory of Dopaminergic Degeneration in Symptomatic and Pre-Manifest Parkinson's

Dr. Michele Matarazzo, a neurologist with the Pacific Parkinson's Research Centre at the University of British Columbia, is tackling an old medical challenge with some of the world's most advanced technology.

The challenge is to understand a fundamental change in the brains of people with Parkinson's disease as their condition advances. More specifically, the goal is to learn the pattern of dopamine loss in the brain, since dopamine is the molecule controlling the body's ability to move.

Matarazzo is using Positron Emission Tomography (PET), a sophisticated imaging system that takes advantage of signals produced by very small amounts of short-lived radioactive agents called isotopes, which are injected into a patient's body. When tagged to particular tracers that seek out dopamine in the brain, these isotopes reveal the metabolism of dopamine at the molecular level, something that's impossible to see any other way.

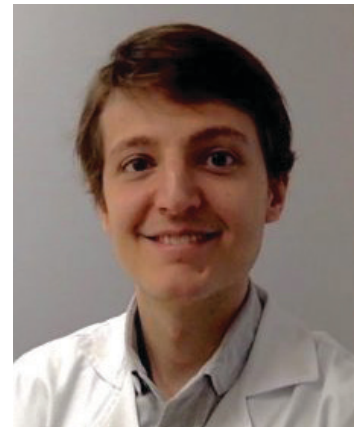
This crucial information helps measure the impact Parkinson's disease is having on the brain.

Matarazzo wants to track Parkinson's progress even before people experience symptoms, until the disease's more advanced stages over several years.

The fact the Pacific Parkinson's Research Centre already has a database of patients' PET scans taken at diagnosis, then four and eight years later, will make the study easier.

"If you're going to declare war, you have to know your enemy as well as you can," says Matarazzo.

He got to know this particular enemy as a medical resident with a prominent Parkinson's disease research group in Madrid. He encountered a young patient who had spent three years being treated for mental illness with anti-psychotic drugs that had left him completely paralyzed. When Matarazzo



PROJECT GRANT

\$100,000 over 2 years funded by Parkinson Society British Columbia through the Parkinson Canada Research Program

RESEARCHER

Dr. Michele Matarazzo

INSTITUTE

Pacific Parkinson's Research Centre at UBC

examined him more closely, he realized the man might instead have Parkinson's.

"When we saw him at age 36 he couldn't even move," Matarazzo says. "We got rid of the anti-psychotics and gave him levodopa. It was an amazing change: within a few of weeks he went from being wheelchair-bound to running in the hallways. That was an important experience."

Matarazzo has had similarly rewarding experiences throughout his career, which combines laboratory research and clinical work with patients. Research is necessarily slow and demanding, he notes, which is why it's vital to work with patients.

"It keeps you motivated, seeing patients every week," he says. "They give you an idea of what is relevant and what is not relevant. They are the ones who give us the questions we are trying to answer and that makes them the goal of our work."

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Register today for Parkinson SuperWalk, Parkinson Society BC's largest annual fundraiser!

September 7-8 | www.parkinson.bc.ca/superwalk

ASK AN EXPERT



Courtney Doherty & Tricia Wallace Discuss Coping Strategies for Mental Health

Courtney Doherty, MCP, RCC, completed her Masters of Counselling Psychology at Adler University in Vancouver. She has been working as a Registered Clinical Counsellor

(RCC) with the British Columbia Association of Clinical Counsellors for over 5 years, and has a part-time private practice. Her personal connection to PD brought her to PSBC 7 years ago. Courtney's father was diagnosed with PD over 15 years ago, and successfully underwent Deep Brain Stimulation surgery. Believing that every individual has the potential to lead a happy and fulfilling life regardless of challenges faced, she brings a unique perspective and skill set to PSBC.



Tricia Wallace, MSN, MCP, has practiced as a registered nurse since 1988 in hospital and community settings, attaining a Bachelor of Science in Nursing (BSN) and a Master of Nursing (MSN) from the University of Victoria. She has recently completed a Master of Arts in Counselling Psychology (MACP)

at Yorkville University. Tricia has extensive experience working with adults of all ages in the field of mental health, including those with neurodegenerative diseases. Tricia recognizes the importance of a strength-based, holistic approach to Parkinson's disease that includes emotional support and skill building.

Courtney Doherty and Tricia Wallace are clinical counsellors with Parkinson Society British Columbia (PSBC). The Society offers free, short-term, confidential, and non-judgemental counselling services for people touched by Parkinson's disease (PD). Counselling provides a safe and structured environment to discuss challenges, process emotions,

and provide you with the extra support you and your loved ones may need. Our counsellors have experience working with people with Parkinson's, and their carepartners and family members. They are able to help in dealing with a combination of issues, such as coping with a diagnosis, life transitions, grief and loss, depression, and anxiety.

What are some common mental health challenges faced by people with Parkinson's?

The mental health challenges faced by people with Parkinson's can vary widely, being influenced by the stage of disease progression, one's support system, and personal histories affecting coping patterns. As clinical counsellors, some of the most common concerns we hear from people with PD have to do with changes in their relationships, questions about the future and disease progression, and grief and loss related to their sense of identity and purpose.

People living with PD face mental health challenges as they adapt to their diagnosis and the changes that it brings. Symptoms of depression, anxiety, and apathy/amotivation are common, and can be attributed to both psychological stressors and changes in brain function caused by the disease. Parkinson's causes interruptions in nerve communication pathways, which affects not only movement, but sensation, motivation, sleep, and emotion regulation (Chaudhuri et al., 2011; Pfeiffer, 2015). Cell loss, changes in brain structure, and inflammation secondary to Parkinson's are all thought to contribute to the development of mental health conditions (Xie, 2015).

What effects do mental health challenges have on people with Parkinson's?

Mental health conditions can have a profound impact on quality of life, and can potentially decrease your ability to respond favourably to treatment. Left untreated, depression, anxiety, and apathy can make self-management difficult, and may keep you from socializing, exercising, and enjoying your usual hobbies.

Some people with PD may also experience impulse control problems as a medication side effect. These

can have a serious and far-reaching impact. They may cause compulsive gambling and shopping, hypersexuality, binge eating, and addictions to the Internet or to other recreational activities (PSBC, 2016). If you are taking any medications associated with these side effects, speak with your doctor, and notify your carepartner or family members so they may be vigilant and prepared to support you in seeking help should you need it.

How do I know if I am experiencing mental health challenges?

Depression, anxiety, and apathy can be identified by examining changes in your day-to-day life. Start by asking yourself the following questions:

- Have my sleep patterns, appetite, energy levels, or sexual function changed recently?
- Am I more irritable and/or worried than I used to be?
- Am I having difficulty concentrating?
- Am I unmotivated to do things?

If the answer to even one of these questions is yes, you may be experiencing some mental health changes, and should speak with your doctor.

The primary symptoms of depression include sadness, hopelessness, irritability, and suicidal ideation. Anxiety disorders are associated with feeling nervous, overly worried, tense, fearful, and restless. Apathy is a lack of interest and motivation in things, but without sadness, hopelessness, and other symptoms associated with depression.

Do I need treatment for mental health changes?

In many cases, changes in mental health and other non-motor symptoms often precede the onset of motor symptoms, like tremor, rigidity, and slowness of movement (Chaudhuri et al., 2011; Pfeiffer, 2015). As motor symptoms progress, so can the mental health conditions associated with PD, therefore it is important to seek early diagnosis and treatment.

It can be difficult to distinguish mental health changes from the changes seen in PD. Be sure to let your healthcare provider know about any changes you or your loved ones have noticed. While it is possible to effectively manage depression, anxiety, and apathy through behavioural changes, a professional can offer guidance, tools, and strategies specific to your situation.

How can people with Parkinson's cope with mental health challenges?

Even with a diagnosis of Parkinson's, and mental health challenges like depression, anxiety, or apathy, it is possible to live a full and happy life. Mental health challenges are not caused by a person's weakness, or a lack of willpower, but are real medical conditions, and legitimate symptoms of Parkinson's that can and should be treated.

Just like with PD, there are many treatment options available to support those with mental health challenges, and many different professionals who can offer various services for the specific symptoms associated with the condition you are experiencing. An outside perspective is important, so if your family, friends, or physician have noticed symptoms of depression, anxiety and/or apathy, be sure to take their concerns seriously, and seek help.

There are many types of medication for mental health conditions, so do not hesitate to ask about your options. If you do start taking these medications, remember that it may take several weeks before you feel better. Early side effects of these drugs usually disappear as your body gets used to them. If the first medication you try does not seem to be helping after some time, your doctor can help you find something that works better for you.

The support of friends and family is crucial, so it is important to be open and ask for help when you need it, even if just to set aside a time to talk to a loved one.

How can carepartners, friends, and family support people with mental health challenges?

Education is a major way that family and friends can support their loved ones with PD. Learning about the disease is essential to cultivating a supportive environment. Once a basic understanding of PD is established, it is important to listen to what is actually going on for the individual with Parkinson's, rather than generalizing, ignoring, or minimizing their situation. When family and friends understand how the disease impacts their loved one, they are able to build greater empathy for that person, as well as offer more effective support. It is also important to recognize when challenges may be beyond one's capacity, and to seek other sources of support, such as counselling or support groups. Attending a Parkinson's support group

CONTINUED ON PAGE 9...

LIVING WELL

Home and Community Care Services for People with Parkinson's and Carepartners

A strong support network is crucial for anyone touched by Parkinson's (PD); however, it can be challenging for spouses, family, and/or friends to cope with taking on caring duties for their loved one living with the disease. To ease the burden for carepartners/caregivers and people with PD, there are many services available across the province to support those with progressive conditions in living their lives to the fullest.

Home and community care services exist to support those who may have limited independence due to chronic healthcare conditions, as well as to provide respite to family and friends who have taken on caregiving roles. These services can be accessed in the community, through adult day services, in residential care or hospice facilities, or at home (HealthLink BC).

It is important for people with PD to know their options and how to access them, even in the early stages of disease progression. For example, you may find value in home supports, like assistance with cleaning, home repairs, or meal preparation, which can save you time and help you conserve your energy for other tasks. If transportation is a challenge for you, some nurses, doctors, dentists, and other healthcare professionals can make home visits, and pharmacies may be able to arrange medication deliveries. Services like these can be instrumental in supporting your independence and self-management abilities by allowing you the flexibility to focus on what matters most to you.

Carepartners can also benefit greatly from additional support. Having access to home and community care services can allow you to maintain your relationship outside of the caregiving situation by enabling you to spend more time together on other activities, like hobbies or travelling. By relieving carepartners of duties that pertain to symptom and medication management, or other medical needs,

they can also become empowered to take on new kinds of caring roles. Carepartners can be strong advocates for the needs of people with Parkinson's – an important role in the PD community. Providing their loved one with PD with additional support also allows the carepartner greater independence, and time for work, socializing, and self-care activities.

The most common and cost-effective options for home and community care can be accessed through your local health authority. Most publicly-funded services are managed by the government, but many private companies also offer their services at a reduced cost through partnerships with health authorities. If cost is a priority for you, keep in mind that high demand for subsidized programs may mean a longer wait and stricter eligibility criteria for access to services. In this case, many community and not-for-profit organizations also offer solutions for those facing barriers to accessing home and community care services through health authorities.

Public Services

Community nursing, rehabilitation, adult day services, home support, caregiver respite, and assisted living can all be accessed through your health authority. To arrange for care, you can contact the home and community care office in your area, and request a needs assessment. Healthcare professionals, including doctors, nurses, pharmacists, and social workers, can also make referrals on your behalf (HealthLink BC).

Needs assessments are conducted by healthcare professionals to determine an individual's eligibility for services, and, where appropriate, to discuss a potential care plan. The healthcare professional in charge of your assessment will seek to understand your healthcare situation, and your needs, values, and priorities. Based on this, they will help determine what services best suit your situation, when and for how long you may need these services, and the potential cost of care. Many people with Parkinson's disease may be eligible to receive subsidies for home and community care services, so your needs assessment will include an evaluation of your financial situation to determine your eligibility. In this case, you should be prepared to provide your income information, pension cheque stubs, and/or recent tax returns.

Public services are limited, and so are provided to those whose healthcare needs are most urgent.

“Urgency criteria” include the overall condition of the individual’s health, the availability of caregivers and community supports, vulnerability to abuse, neglect or self-neglect, and length of time waiting for an assessment (HealthLink BC). Those who are found to be in the most need, and at the highest levels of risk, are deemed to have the most urgent cases, and will have priority access to the appropriate home and community care services.

It is important to remember that you have a right to consent to any service offered to you by your local health authority. Your needs assessment is the perfect opportunity to ask questions and ensure that you are fully informed before making a decision to access the services recommended to you.

If you are found to be eligible for services, a healthcare professional will work with you, your family, and your carepartners to create a flexible care plan. They will also discuss your status of priority, and how long you may expect to wait for access to services. If your situation is not considered urgent, the healthcare professional on your case will refer you to other services that may be helpful in the meantime, and discuss self-management strategies for you and your carepartners/family.

If you are interested in finding out more about the home health services that can be made available to you, call your local health authority’s Home and Community Care office:

Fraser Health | www.fraserhealth.ca | 604-953-4965
Interior Health | www.interiorhealth.ca | 250-469-7070
Island Health | www.islandhealth.ca | 250-388-2273
Northern Health | www.northernhealth.ca | 250-565-2649
Vancouver Coastal Health | www.vch.ca | 604-263-7377

Private & Non-Profit Services

Many prefer to access home and community care services through private companies. If you are ineligible for public services, or want immediate and flexible access, private services can provide you with care based on your needs and priorities. Similarly to public services, private home care, assisted living, or nursing services will pair you with a case manager who will help you build a care plan. Private services can also include meal delivery, personal care, housekeeping, and caregiver

respite. In many cases, eligibility criteria are lower, and services can be accessed on-demand. Some examples include:

- **Nurse Next Door** offers home care services including companionship, nursing care, meal preparation, personal care, transportation, and caregiver relief. The company matches each client with a caregiver who matches their needs and personality, and services can be accessed 24/7. | www.nursenextdoor.com
- **Bayshore HealthCare** is one of the largest home and community care services in Canada. They provide medical and non-medical home healthcare, as well as specialized nursing, physiotherapy, occupational therapy, pharmaceutical, and other services, which can be accessed both privately and through health authorities. | www.bayshore.ca
- **Silver Valet Dental Care** is an on-site oral health service offering preventative and restorative care for those who may not be able to visit a traditional dental office. Treatment is provided in fully-equipped and accessible clinic vans. | www.silverdental.ca

Some non-profit organizations offer free or low-cost services, which are most often volunteer-led. In some cases, eligibility criteria may apply, and services may be reserved for vulnerable communities, low-income families, or those who cannot access care through a health authority. However, most communities will have flexible options, and referrals can be given through your local home and community care office. Options include:

- **Better at Home** is a United Way program that supports seniors with activities of daily living through various services offered throughout the province. Volunteers may assist with many activities, including transportation, light housekeeping, friendly visiting, yard work, or grocery shopping. | www.betterathome.ca
- **Care BC** runs respite care services for seniors and individuals with newly-acquired disabilities, as well as the low-cost Meals-on-Wheels meal delivery program. | www.carebc.ca

Assisted Living

For those who are still largely independent, but may need longer-term support with activities of daily living like meal preparation and household chores, assisted living facilities can be a valuable option. As symptoms

advance, this option may become a necessity to ensure needs are met without caregivers experiencing burnout.

Assisted living residences provide holistic care in a safe and comfortable environment, and an around-the-clock emergency response system. Alongside medical and personal care, these residences also support seniors through activity programming and opportunities for socialization.

Although sometimes stigmatized as restrictive and/or degrading, assisted living facilities exist to enhance independence by reducing isolation and risk of harm, and relieving some of the responsibility of self-management. It also allows carepartners/caregivers the opportunity to refocus on their relationship with their loved one, whether as a spouse, family member, child, or friend.

The piece below, reprinted from our Viewpoints archives, offers an important perspective on assisted living, and how carepartners can cope with this transition.

FROM OUR ARCHIVES

Care Giving After Placement

Viewpoints, Summer 2002

The possibility that placement in a care facility will become necessary, especially if the care recipient has a degenerative condition, is an obstacle which may seem insurmountable to many family caregivers. The decision to place an individual into the care of a facility or institution poses what may be considered the ultimate negative choice for caregivers. This decision may provoke stress and is surrounded by conflicting values. A caregiver may need to accept that he/she can no longer meet the needs of the care recipient or that the situation is beyond his/her control. This may prompt feelings of guilt (e.g., for abandoning the care recipient or feelings of failure at caregiving) or anger at oneself, one's family or the care recipient for "causing" the situation in the first place. Although the actual deciding factor may differ from family to family (e.g., lack of recognition of family members, incontinence),

ultimately the balance of needs between the care recipient (e.g., nursing care, safety issues) and the caregiver (e.g., health, well-being) is tipped and placement becomes yet another necessary transition in the ongoing caring relationship.

As with many transitions, adjustments must be made and challenges overcome. After placement, a caregiver does not give up her/his role but remains involved in new and different ways. The pressure of being "on call" all of the time and the physically draining efforts of providing care are likely to be relieved by placement. The new challenges faced by the caregiver centre around finding ways to become an active member of the healthcare team and participate in planning care. Family caregivers bring a unique, historical, and intimate understanding of the person that can greatly assist staff in understanding how to meet the individual's needs.

Placement often provides increased opportunities for social and recreational activities for both the patient and the caregiver. Although placement may allow for the physical and social care needs to be better met, family and friends continue to be the ones most able to reach the emotional needs of the afflicted individual. Through interactions with staff, involvement in facility programs, and monitoring of care provided, the caregiver's role is extended into new frontiers. This shift in responsibilities from full-time provider of care to visitor, advocate, and facilitator also allows the caregiver an opportunity to return to some previous activities, spend relaxed time with close friends, or start new projects.

There is no denying that the decision to place the care of a loved one in the hands of another is difficult and pivotal. The consequences of placement pose new challenges to be overcome in terms of shifting roles and adjusting to losses (e.g., separation, companionship). Think about the issue of placement before a crisis. Ponder, discuss, and prepare for placement with assistance of family members, friends, support groups, clergy, or counsellors. These challenges should not be faced alone.

—

By Holly Tuokko, Psychologist, Elderly Outreach Services, Victoria. Reprinted with permission from the Transmitter, a publication of the Victoria Epilepsy and Parkinson's Centre (HeadWay).

ASK THE EXPERT: COPING WITH MENTAL HEALTH CONT'D

can be very beneficial to recognize that no one is alone on their journey, and to learn what has helped others deal with similar challenges.

Increasing communication about mental health is another way to effectively support loved ones with depression, anxiety, and other challenges. Carepartners, relatives, and friends are often eager to “fix” the person with PD, and so find themselves helping with activities of daily living (e.g., putting on a coat or buttoning up a shirt). Sometimes, this is unnecessary and could hinder the individual with PD, who may not want this type of help. It is important for family and friends to ask the individual with PD what they need, and listen to them. Listening to others can be empowering to all parties involved, and can provide a foundation to move forward together.

Another way that friends and family can show their support is by exercising patience and empathy, both for their loved one with Parkinson’s and for themselves. This can also help prevent carepartner burnout, enabling them to provide support on a long-term basis. As counsellors, we see the difference in clients who choose to develop these capacities for their loved one and themselves. They are often more grateful, relaxed, and grounded.

While family carepartners, caregivers, relatives, and friends can act as valuable sources of support, it is important to recognize that they are not trained mental health professionals. Seeking professional help may be necessary in certain situations.

How can counselling help people with Parkinson’s?

Parkinson’s disease is a very complex condition; it has life-changing effects on the person diagnosed, as well as their carepartners, family, and friends. Access to counselling is important because it provides a safe space to explore challenges, establish a support network, and to gain coping strategies to move forward.

Parkinson Society BC offers short-term counselling services — up to 8 sessions — to tackle the most pertinent issues that an individual is facing. Depression, anxiety, and/or apathy are among some common challenges that individuals with PD seek counselling for. Other challenges that clients bring to counselling include grief and loss, relationship struggles, panic attacks, hallucinations, impulse control problems, and inadequate coping strategies.

Once 8 sessions have been completed, and where long-term counselling is identified as being beneficial, the individual(s) will be referred to other resources. Counselling is a very individualized process, and clients can expect a tailored approach. As counsellors, we always use evidenced-based approaches.

Additional Resources

Parkinson Society BC Counselling Services

This summer, we say goodbye to Courtney Doherty as she departs for maternity leave. In her absence, we will be welcoming Tricia Wallace into the role of Education & Support Services Coordinator and Counsellor. Tricia will be taking counselling clients two days per week.

We have also welcomed a new counselling intern, Natalie Nunez, who is completing her Masters in Counselling Psychology at City University in Vancouver. She is available once a week on Thursdays.

Visit www.parkinson.bc.ca/counselling to learn more about our counselling program. Interested in making an appointment? Call us at 1-800-668-3330 or email info@parkinson.bc.ca.

Online Resources

Parkinson’s Caregivers Guide | bit.ly/pdcaregiverguide
Apathy Helpsheet | bit.ly/pdapathy
Grieving & Loss Helpsheet | bit.ly/carepartnergrieving
Caring in the Family Helpsheet | bit.ly/pdffamilycare
Cognitive Health Helpsheet | bit.ly/pdcognitivehealth
Mental Health & PD Helpsheet | bit.ly/pdmentalhealth

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MOVING FORWARD

together

QUESTIONS? CONTACT US!

Phone: 604-662-3240
Toll-Free: 1-800-668-3330

STACEY DAWES

Manager, Education & Support Services
sdawes@parkinson.bc.ca

CAROLINE WIGGINS

Education & Support Services Senior Coordinator
cwiggins@parkinson.bc.ca

Parkinson Society British Columbia invites all members of the Parkinson's community in BC to join us for an exciting opportunity to learn about recent scientific breakthroughs and disease management techniques.

Moving Forward, Together will foster an educational and inspirational space for enriching the connection between people with Parkinson's, carepartners, friends, and healthcare professionals. The return of this much-anticipated event will feature prominent local, national, and international presenters who will speak to topics related to the treatment and management of Parkinson's and its associated challenges. The conference will include two morning plenaries and eight afternoon breakout sessions, which aim to offer a diversified itinerary for all attendees.

This year, we are offering a new breakout stream specifically for healthcare professionals to attend and expand their knowledge of Parkinson's disease.

SAVE THE DATE

SATURDAY, OCTOBER 26

HILTON VANCOUVER METROTOWN HOTEL



PLENARY SPEAKER

MARK MAPSTONE, PHD is a translational neuroscientist. His goal is to translate discoveries about the aging brain into practical and implementable approaches for successful cognitive aging at the individual level. In his presentation at *Moving Forward, Together*, Dr. Mapstone will give an overview of non-motor symptoms of Parkinson's, and discuss strategies to promote cognitive health for people living with the disease. He will end by describing some of his work, and the work of others, on early detection of Parkinson's using biomarkers obtained from blood. From his research, there is hope to develop reliable biomarkers for clinical use.

WITH BREAKOUT SESSIONS ON...

Nutrition, cognitive changes, fall prevention, symptom and medication management, and more!

**MORE SPEAKERS & BREAKOUT SESSIONS
TO BE ANNOUNCED. STAY UP-TO-DATE AT
[PARKINSON.BC.CA/MOVINGFORWARD](https://parkinson.bc.ca/movingforward)**



TRAVEL SCHOLARSHIPS AVAILABLE

Parkinson Society BC will be offering a limited number of scholarships for people with Parkinson's, family carepartners, and healthcare professionals who reside in BC to attend *Moving Forward, Together*. Scholarships will help to cover registration, accommodation, and travel costs. Online applications opening soon.

LIVING WELL

Singing for Parkinson's

Many people with Parkinson's disease (PD) have found that singing exercises may help to alleviate some of their challenges with speech and swallowing. Over 80% of people with PD experience these issues, but therapeutic approaches are limited, and may not work for everyone. Exercising the muscles used in speech and swallowing is a good strategy for self-management of these symptoms.

Voice and Swallowing

Using the same muscle groups as speech, singing provides a more controlled vocal exercise. For those who experience a soft voice, singing can improve loudness by exercising the throat, chest, mouth, and facial muscles to strengthen them, and increase mobility (Vella-Burrows et al., 2012). Other problems, like stuttering or slowed speech, can also improve with singing, as it stimulates regions of the brain responsible for articulation in speech.

Singing is a proven way to practice laryngeal and respiratory muscle control, as well as extension of the diaphragm and chest. The larynx produces sound in both speaking and singing, while the respiratory system controls the pressure used to adjust pitch and volume. Both of these muscle groups can be compromised in PD, so regular exercise is important for maintaining your abilities.

The larynx and other muscles in the throat are involved in blocking food from entering the airway during swallowing. Strengthening this muscle group through exercise can reduce the risk of choking. Strong lungs, diaphragm, and chest muscles are also important for coughing, which expels any food particles or liquids from the lungs. A weak cough may result in a buildup of bacteria in the lungs, causing pneumonia.

Many people with PD also experience a dry mouth from decreased saliva production, which can contribute to problems with swallowing, and risk of choking. Studies have shown that singing can increase saliva production, improving the oral environment (Sakano et al., 2014).

Motor Symptoms

Singing requires control of the chest and diaphragm, which are also used for postural stability. Strengthening these muscles and training your control of them can help you maintain good balance, and reduce your risk of falling. However, in addition to these direct effects of physical exercise, singing may also improve your balance and motor functioning on a neurological level.

The regions of the brain responsible for controlling movement and maintaining a steady gait also control how you process rhythm. Auditory stimulation, including rhythmic music, has been shown to help people with PD who experience freezing of gait, or problems with their walking speed, cadence, or stride length. Research suggests that by singing to produce your own auditory stimulation, you may also be better able to control your gait, and cue movement after freezing (Harrison et al., 2017).

Memory and Mood

Parkinson's may bring changes to your sense of identity and belonging. Many find comfort in new, creative hobbies, and group activities with their peers. Parkinson's singing groups are a valuable outlet for creativity and stress relief, where voice challenges can be met with empathy, compassion, and understanding. Participating in a shared activity with other people with PD and carepartners can be important for building relationships and community outside of the support group setting.

In a Japanese study examining the effects of group singing on seniors, the activity was found to decrease levels of cortisol, a hormone linked to stress and fear (Sakano et al.). The same study provided participants with questionnaires before and after singing, which guided them to indicate their levels of certain emotions. After singing, most people reported improvements in feelings including comfort, pleasure, light-heartedness, relief, and relaxation, and decreased levels of confusion and tension.

Socialization

Chris and Harold Olsen facilitate a singing group in Maple Ridge with members of their PD support group. The Tremble Clefs are a friendly, non-judgemental group of peers, and they welcome anyone who would like to stop in and sing a few songs with them, including carepartners, friends, and family.



As a person with PD, Chris has found great benefit from singing. “I’ve gained confidence in my ability to sing, which rolls over into other areas of my life,” she says.

The pair say the purpose of their group is three-fold: it is a fun, social outlet, a way to exercise the voices of members with PD, and a contribution to their community. The Tremble Clefs perform monthly at their local hospital.

“We have lots of fun, which brings out the lighter side of everyone, and the connections our group has made with each other have broadened into solid friendships,” says Chris.

Harold, Chris’ husband and carepartner, has a passion for music and a background in teaching, which led him to organize the group after hearing of the benefits of similar singing programs for PD. “The singing group is a way of not only having fun, but it has given [Harold] a way to keep teaching, and stay musically connected,” says Chris.

This singing group has found great success, and Chris and Harold regularly receive positive feedback from members. “We have seen confidence grow in others,” says Chris, who has noticed a commitment in every member of the group to attend practices. She sees this as “a strong indication of how important this is to them”.

Additional Resources

SongShine Program

Songshine is an effective music-based vocal program for persons whose speech has been affected by

Parkinson’s disease, stroke,

other neurological disorders or aging voices. The program builds voices with a holistic approach that integrates breath awareness and body alignment, vocalizes (singing exercises), singing in community, diction and articulation exercises, creative imagination, becoming a character (role playing), and emotional engagement. The program is available in communities across the province. Visit www.parkinson.bc.ca/songshine to view class schedules and find out how to register.

Sources

Harrison, E.C., McNeely, M.E., and Earhart, G.M. *The feasibility of singing to improve gait in Parkinson’s disease*. *Gait & Posture*, 53. 224-229. <https://doi.org/10.1016/j.gaitpost.2017.02.008>

Sakano, K., Ryo, K., Tamaki, Y., Nakayama, R., Hasaka, A., Takahashi, A., Ebihara, S., Tozuka, K., and Saito, I. (2014). *Possible benefits of singing to the mental and physical condition of the elderly*. *BioPsychoSocial Medicine*, 8(11). <https://doi.org/10.1186/1751-0759-8-11>

Vella-Burrows, T., and Hancox, G. (2012). *Singing, Wellbeing, and Health: context, evidence and practice*. Sidney De Haan Research Centre for Arts and Health. Canterbury Christ Church University, Kent, UK. <https://artshealthnetwork.ca/ahnc/ngingandpeoplewithparkinsons.pdf>

PARKINSON SUPERWALK®



This September, you can give hope to 13,000 British Columbians living with Parkinson's disease.

PARKINSON.BC.CA/SUPERWALK



Since 1969, Parkinson Society BC has sought to empower people with Parkinson's disease, including carepartners and family. We take pride in providing people with tools and information for the purposes of symptom management and self-care.

Here's where you come in. We need your help to expand our efforts so we can reach more people, and ensure that every British Columbian touched by the disease knows that they are not alone in their journey.

Parkinson SuperWalk is the single most important fundraiser of the year for our Society. We invite you to join us at your local walk this September!

Register today or make a donation online to support our programs, services, advocacy efforts, and research contributions.

Parkinson SuperWalk in British Columbia is operated by Parkinson Society British Columbia under license from Parkinson Canada

**THANK YOU TO OUR
PROVINCIAL SPONSOR**



QUESTIONS? CONTACT US!

Phone: 604-662-3240

Toll-Free: 1-800-668-3330

100 MILE HOUSE

Centennial Park
Saturday, September 7

ABBOTSFORD

Mill Lake Park
Sunday, September 8

BURNABY

Confederation Park
Sunday, September 8

CASTLEGAR

Millennium Park
Saturday, September 7

CHILLIWACK

The Landing Sports Centre
Saturday, September 7

COMOX VALLEY

Courtenay Airpark Playground
Saturday, September 7

CRANBROOK - VIRTUAL WALK

Participants are invited to walk at a location, date, and time that works for them.

KAMLOOPS

Riverside Park,
Rotary Bandshell
Saturday, September 7

KELOWNA

Waterfront Park,
Concession Plaza
Saturday, September 7

LANGLEY

Aldor Acres Family Farm
Saturday, September 7

NANAIMO

Maffeo Sutton Park,
Nanaimo Lions Pavillion
Sunday, September 8

OLIVER

Oliver Community Centre
Sunday, September 8

PARKSVILLE

Parksville Community Park
Saturday, September 7

PITT MEADOWS/ MAPLE RIDGE

Pitt Meadows Seniors
Activity Centre
Saturday, September 7

PORT ALBERNI

Victoria Quay Walkway
Sunday, September 8

POWELL RIVER

Timberlane Park Track
Sunday, September 8

PRINCE GEORGE

Lheidli T'enneh Memorial Park,
Band Shelter
Saturday, September 7

SALMON ARM

McGuire Lake Park
Saturday, September 14

TERRACE

Grand Trunk Pathway,
Millennium Trail
Sunday, September 8

VANCOUVER

Stanley Park,
Ceperley Playground
Sunday, September 8

VERNON

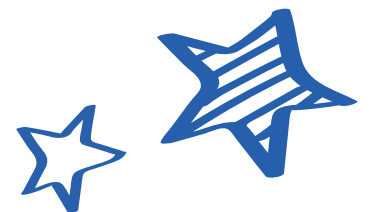
Polson Park
Saturday, September 7

VICTORIA

Esquimalt Gorge Park
Saturday, September 7

WHITE ROCK

Kintec Store Parking Lot
Sunday, September 8



Walk locations, dates, and times are subject to change. For the most up-to-date information, visit www.parkinson.bc.ca/superwalk.

BETTY HUM

Resource Development Officer
bhum@parkinson.bc.ca

STEPHANIE LOWE

Events Assistant
slowe@parkinson.bc.ca

MIRELA PRIME

Resource Development
& Volunteer Coordinator
mprime@parkinson.bc.ca

NEWSWORTHY

UPCOMING EDUCATION EVENTS

Regional Conference, Kelowna

Our regional conferences are immersive and interactive opportunities for people affected by the disease to learn from leading experts while connecting with the Parkinson's community.

Topics covered at this conference will include:

- **New & Advancing Therapies** | Dr. Daryl Wile, Movement Disorder Specialist in Kelowna
- **Sleep & Parkinson's** | Dr. Ron Cridland, MD with the Canadian College of Family Physicians and Fellow of the American Academy of Sleep Medicine
- **Living with Purpose & Resilience - "I Am Not My Disease"** | Debra Coffey, Registered Professional Counsellor

Date: Saturday, June 22
Time: 1:00pm - 4:30pm
Location: Ramada Hotel & Conference Centre
2170 Harvey Ave
Cost: Member \$15 | Pair \$25
Non-member \$25 | Pair \$45

Communication & Swallow Workshop, Kelowna

This full-day interactive and participatory workshop, led by Registered Speech Language Pathologist Sherri Zelazny, will focus on the communication and swallowing challenges faced by people with Parkinson's. This event is open to those already experiencing communication and swallowing challenges, as well as those who wish to be proactive in their treatment.

Date: Saturday, September 28
Time: 10:00am - 2:30pm
Location: Ramada Hotel & Conference Centre
2170 Harvey Ave
Cost: Member \$25 | Pair \$40
Non-member \$35 | Pair \$60

Ask the Expert Webinar: Developing Tools to Discover New Therapeutic Agents

Join us on July 16, as Dr. Roger Ashmus from Simon Fraser University presents his research on developing tools to target the protein GCase (glucocerebrosidase). Gene mutations in people with Parkinson's cause a deficiency in GCase, which is one of the key risk factors for disease onset. Studies have shown that treating this deficiency could help prevent the progression of Parkinson's in mice models. Dr. Ashmus uses a combination of organic chemistry, chemical biology, and cell biology in hopes of discovering new therapeutic agents that increase GCase activity.

Date: Tuesday, July 16
Time: 10:00am - 11:00am
Cost: Free

TO VIEW OUR FULL EDUCATION EVENT LISTINGS & REGISTER ONLINE, VISIT WWW.PARKINSON.BC.CA/EVENTS

Thank you to our fundraisers & donors!

Chocolate & Beer

Filled with decadent chocolates, flavourful craft beers, and live music by The Ghost of Blood Alley, this year's sold-out Chocolate and Beer Tasting raised \$3,080! This total includes generous contributions of \$891 by Take a Fancy Chocolates, and \$430 from the hosting brewery, Moody Ales. Special thanks to organizers

Sherri and Julian Zelazny, Becks D'Angelo of Take a Fancy, and Cory Hawkins, Rory Chudley, and Stephen Dolinski of The Ghost of Blood Alley!

Ice Hockey Donations

Philip Konrad collected \$222 in donations from his hockey club! When he plays goalie, Philip's teammates put forward a loonie for every goal scored against him - and many generously give too much! "It adds laughs to the games and raises Parkinson's awareness," he says. Thank you, Phillip!

Additional thanks to...

- **Stephanie O'Connor** collected \$625 in donations on her birthday, in honour of her father with PD.
- **Me-n-Eds Pizza Parlours** donated \$350 from sales of their heart-shaped pizzas this Valentine's Day.

SUPPORT GROUPS

Good Vibrations

This sunny Thursday morning at 9:20am, the first of 14 members of the Good Vibrations Gang (our all-women support group) walk through my front gate followed by others who step, waltz, stagger, shuffle, and trip into the house. Some are on the arm of their husbands, some arrive via carpool, two use their canes, one rides her bike across town. It's the second Thursday of the month, our regular meeting day.

The budding Spring, fresh air, and blue sky make it easy for us to forget we're all card-carrying members of the exclusive club of Parkinson's People.



They settle into the various seating options in the living room, and eagerly engage in greetings and gratitudes. Two have been travelling in Europe, one recently recovered from a weekend illness, another from a hip replacement. One of the women, whose voice was deeply affected as a result of Deep Brain Stimulation, is sporting a microphone, which she uses to great advantage to tell her stories. There's laughter and chatter, and offers to help. The first hour flies by as we eat our Hummingbird Cake, drink coffee, tea, and water, and debrief the Gala Fundraiser our local support group hosted this past Saturday.

Gradually, the conversation turns towards our Parkinson's disease, and how we're handling our meds, sleep issues and crazy dreams, constipation, dyskinesia, dystonia, aches and pains, fears of a Sinemet shortage, the Neupro patch and who's actually using it, timing of meds, travelling with meds, and medical marijuana options and access. The newer members listen intently, and ask questions timidly; others with more experience have fewer inhibitions and offer commentary that diffuses the fear and uncertainty of tomorrow.

These are conversations unique to our little gathering. Because we all will eventually share the same issues, and walk in someone else's shoes, there is a surprising air of acceptance and positivity. We are girlfriends with an inherent empathy for each other, bound by this insidious, degenerative disorder. We give each other a voice, respect, and love. That second hour flies by, the doorbell rings as husbands arrive to pick up their wives, hugs are exchanged, and "thanks" echo down the hallway. Fourteen women at various stages of Parkinson's disease head back home, filled with hope and happiness.

Next month we will all still have PD, and yet eagerly anticipate the next gathering, none of us cured.

Submitted by Debbie Hartley.



SHARE YOUR STORY!

This year marks 50 years of service for Parkinson Society BC. We would not have reached this milestone without the support of our community. That's why this year, we're celebrating you! Submit your story today and have a chance at being featured in the next issue of Viewpoints!

For more information, visit parkinson.bc.ca/50 or contact Jovana Vranic at jvranic@parkinson.bc.ca.

CAREPARTNER'S CORNER

Adaptations That Mark Our Journey

In the early 1990s, Betty and I were absorbed in satisfying careers; and outside of our employment, given to volunteering. Our children were nearing the end of high school, with exciting opportunities beckoning on their horizons.

Uncharacteristically, Betty began exhibiting increasingly noticeable physical changes. Getting out of her car was laborious. Her feet felt heavy, making tripping a hazard, and perplexingly, writing legibly was compromised. Friends expressed concern over symptoms they observed. And Betty herself was experiencing unusual fatigue.

We initially thought these changes resulted from the stress of caring for her aging parents while balancing full-time teaching, and other commitments. In 1995, as a result of accumulating symptoms, we agreed that it was time for Betty to see a neurologist. After a surprisingly brief examination, his verdict was terse: you have Parkinson's disease. A new chapter in our journey had begun, and to our combined trepidation and relief, we had a name for symptoms with whom we would learn to share close company.

We took some time processing this news. After learning that Parkinson's disease was progressive and incurable, we wrote a letter to our extended family and close friends, disclosing Betty's diagnosis. It was our first attempt denying this invader control over the pace of living.

Betty was acutely aware that managing a healthy classroom environment in a junior high school setting would be ever more daunting. As a result, she decided to work part-time for several years, then retire in 1998, somewhat earlier than anticipated. Two years later, considering whatever good years we had ahead of us, I also ended my career. Betty and I chose to pursue our retirement dreams, which included more international traveling and volunteering. That was some 20 years ago. The intervening time has been fulfilling, and in ways we could not have anticipated, rewarding.



Personal, Everyday Adaptations

Since our journey with Parkinson's coincided with traveling on the aging express, we soon began negotiating everyday adaptations, never quite certain what the source of these changes might be. One very consequential change has meant finding our comfort in a much smaller living space, and discovering the liberty of living more with less. In 2013, we sold the memory-filled house we had lived in for 25 years, and settled into a condominium half the size. We left the garden we loved, a large sewing room, and garage, in exchange for closer neighbours and new hobbies.

Living with Parkinson's has taught us to calibrate new meaning to old words. For instance, going out for a date at 79 has a completely different buzz about it than it did at 29. Encroaching limitations notwithstanding, we choose to continue sharing the intrinsic joy of company and conversation, often with our children and grandchildren, nieces and nephews, and others who have become like family.

Non-negotiable is the embrace of new schedules that call for more afternoon naps, and a cell phone alarm which regularly reminds me when Betty's next dose of Sinemet is due — to which, recently, our neurologist added a "patch," that must be changed every 24 hours. My daily schedule now significantly revolves around managing Betty's medications.

We are learning that shorter days and longer nights quite match our present needs for work and rest. Now, our frequent schedule of news at 8:00 easily morphs to snooze by 9:00. Evening activities we used to enjoy have been rescheduled into daytime outings.

As all persons living with Parkinson's become aware of, there is an important link between PD and diet. Granular foods like rice and stringy meats have become compromising for Betty's swallowing. Increasingly, meal preparation now involves foods moist in content and nutrient-dense. Despite these changes, we still enjoy discovering new dishes from the variety of international restaurants in our neighbourhood, in addition to enjoying jars of soup and fresh baking from neighbours who have become an important part of the support network.

Adaptations That Reach Deep Into Our Way of Doing Things

As we have discovered, it is not uncommon for people with Parkinson's to experience weakening voice muscles. For us, the consequence is that as Betty's words become less audible, my hearing must become more acute.

Another major adaptation, especially for Betty, has been loss of mobility, confining her to a wheelchair. I have observed at close range that it takes a sturdy, mature disposition to ensure that mobility reduction does not imperil personal confidence.

Mobility reduction – such an obtuse turn of phrase that so easily masks its consequences. We certainly travel less, and have allowed our passports to lapse, a major decision in our journey. We simply choose not to risk crossing international borders, health insurance policies notwithstanding. In legal parlance, the term “pre-existing conditions” is quite sufficient for us to redefine the meaning of adventure.

Far-reaching have been the adaptations in the way we manage necessary domestic duties in our home. Over time, as Betty's hand-eye coordination has deteriorated and her energy diminished, duties we happily shared in our marriage such as shopping, food preparation, and laundry, have now become the responsibility of her caregivers. Her favourite hobbies, like sewing and trying new recipes, have been replaced with learning what she can about current PD research, and increased energy devoted to basic activities of daily living.

Operatic performances thrive on solo work. By contrast, living with Parkinson's prizes networking. Betty and I feel indebted to Parkinson Society BC for emphasizing the importance of team building, which for us includes not only medical specialists, but also therapists, a nutritionist, several ladies who

assist Betty with her daily routines, a once-a-week day visit to an adult daycare center which rewards Betty with new companions, exercise routines, and hobbies. And importantly, our team includes a most appreciated group of family and friends whose ongoing encouragement is sustaining for us.

Social Adaptations

While Betty and I thoroughly enjoyed community volunteering with several local history groups, our faith community, supporting newcomers to Canada, our children's sports, and musical interests, the word “Committee” is no longer in our working vocabulary. Now we are discovering joy in letting go of responsibilities, while encouraging the next generation to pick up the baton.

Not unwelcomed at this stage is the shrinking circle of our social contacts, commensurate with our diminishing energies. Large group events, concerts, or community lectures, which have been central to our interests, we have quite contentedly replaced with more intimate times, often over a supper with a few friends at our home, or in a local restaurant.

Some Continuities, Adaptations Notwithstanding

While changes inexorably continue to shape our journey, some aspirations remain unaltered. We continue to work at maintaining vitality in our marriage, now 55 years in the making. What a rich journey this has been.

It is our continuing desire to remain mentally alert and spiritually alive. Shakespeare certainly had it right that valiant souls die only once. For us, a core of close friends is a safe place to vent our pains and consolidate our gains. Having lived and worked internationally for many years, we value cross-cultural friendships, and seek to allow space for new relationships, presently including a recently arrived Syrian family. Getting to know this family has helped us understand the calamity of distant international conflict, just as living with PD has helped us understand more of the complex character of this disease and those who journey with it.

The bottom line for us is that we strive to remain alive to that and those who inspire healthy perspectives. These friends include the members of our local Parkinson's support group, from whom we continue to draw inspiration by the heroic examples they set before us.

Contributed by David and Betty Giesbrecht.

CELEBRATING 50 YEARS OF SERVICE

Parkinson Society British Columbia was established with a mission to empower people with Parkinson's in British Columbia through providing resources and services to enable self-management, self-reliance, and self-advocacy. In 2019, we celebrate 50 years of service to our community.

We invite you to join us in celebrating this milestone. This year, we hope to extend our reach further, and strengthen our impact greater than ever before – within the Parkinson's community and beyond.

GET INVOLVED

We believe that every person affected by Parkinson's disease deserves to know that they are not alone. Help us spread the message, and let them know that we are here to help. Tell us about how Parkinson Society British Columbia has helped you, using the hashtag #PSBC50!

You can also submit your story for a chance to be featured in Viewpoints, Good News, on our website, or on social media! We encourage you to share your journey with Parkinson's disease, testimonials about our programs and services, or anecdotes from your support group!

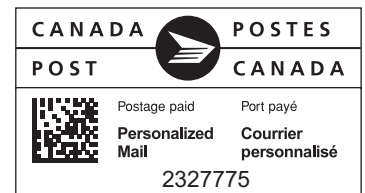


**HELP US CELEBRATE 50 YEARS OF COMMUNITY.
GET IN TOUCH & SHARE YOUR JOURNEY WITH
PARKINSON'S DISEASE TODAY.**

JOVANA VRANIC
Marketing & Communications Coordinator
jvranic@parkinson.bc.ca

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