

VIEWPOINTS

SPRING 2019

A QUARTERLY NEWSLETTER
BY PARKINSON SOCIETY
BRITISH COLUMBIA

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50 YEARS OF
SERVICE

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PARKINSON'S
AWARENESS
MONTH

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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 (Vancouver), New Westminster, Osoyoos/Oliver, Parksville/Qualicum, Parksville/Qualicum Caregivers, Penticton, Port Alberni, Powell River, Prince George, Quadra Island, Quesnel, 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, West Vancouver Carepartners, White Rock, White Rock Carepartners, YOPD Online

EDITORIAL STATEMENT

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RESEARCH

Clinicopathological Investigations of the Substantia Nigra in Parkinson's Disease

Researchers who study Parkinson's disease (PD) have long known that dopamine-producing cells in a region of the brain called the substantia nigra are central to the reason people develop this degenerative illness.

When dopamine-producing cells die, their death affects the body's ability to control movement. Some people also have other symptoms, including a decline in their judgment and reasoning ability, freezing in place, and other walking difficulties that lead some researchers to suspect the diagnosis of Parkinson's is actually being applied to a group of different, though related, conditions.

At Laval University, Professor Frédéric Calon thinks it's time to take another look at the substantia nigra.

Much of the research used to develop treatments for PD, such as levodopa medication, was based on studies of tissue samples collected 50 years ago.

Using current knowledge about the role of genes and proteins in contributing to PD, Calon will correlate samples of brain tissue from people who had PD with the case studies that described the symptoms of their illnesses.

"What's surprising is there have not been that many studies focused on the substantia nigra of people who died with Parkinson's disease," says Calon. "We think that looking directly in the brain... can help develop new treatments."

Calon hopes to find structural changes in the substantia nigra that will point to differences in the subtypes of PD.

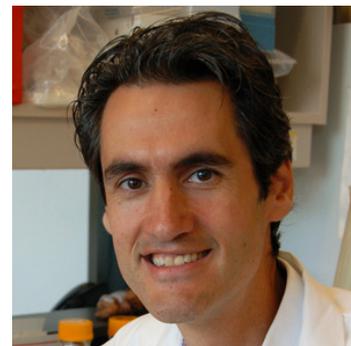
DO YOU HAVE PARKINSON'S RELATED LEGAL ISSUES?

Blakes

Through a partnership with Parkinson Society BC, the law firm of Blakes, Cassels & Graydon LLP offers free of charge legal services to people with Parkinson's in BC.

The Litigation Support Program for Blakes addresses legal issues such as discrimination against individuals with Parkinson's in the workplace, discrimination in accommodations, services, or facilities that are generally available to the public; and wrongful denial of disability insurance, or denial of government services.

If you have a legal problem relating to Parkinson's disease, please contact Jean Blake, CEO, at jblake@parkinson.bc.ca for more information.



PROJECT GRANT

\$45,000, partially funded by Parkinson Society British Columbia (\$20,000) and the Quebec Research Fund for Parkinson's through the Parkinson Canada Research Program

RESEARCHER

Frédéric Calon

INSTITUTE

Laval University

"Based on what we learn, perhaps we can develop new treatments or new ways to prevent the progression of the disease," he says.

Calon, a biochemist and a pharmacist, thinks he may find differences in the substantia nigra of people who had gait problems, such as freezing episodes, compared to the substantia nigra of people who experienced more stiffness, and tremor, for example.

Calon's work is possible because of a collection of brain samples, known as a brain safety deposit that Drs. Ali and Alex Rajput have collected alongside histories of their patients in Saskatchewan. "It's really a pan-Canadian collaboration," Calon says.

Calon, who works closely with the Parkinson's community in Quebec, is motivated by the experiences of the people with Parkinson's he meets.

"I have confidence that it's possible to improve the treatment of Parkinson's disease," he says.

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ASK AN EXPERT



Sherri Zelazny, MA RSLP, Discusses Communication & Swallowing Difficulties in Parkinson's Disease

Sherri Zelazny has been a speech-language pathologist for over 30 years. She is LSVT® certified, and has been involved with the

Parkinson's community since the beginning of her career. She also volunteers her time to facilitate Parkinson Society British Columbia's Communication & Swallow Workshops, and serves on the Board of Directors.

What are some of the common speech & communication problems in Parkinson's disease? What about swallowing problems?

Hypokinetic dysarthria is the term used to describe communication problems in Parkinson's disease. The most common communication difficulty that people with Parkinson's disease (PD) experience is low vocal volume or soft voice. This is something that can occur even before a formal diagnosis. Other communication changes can include hoarseness, mumbling, and changes in speaking rate.

Dysphagia is the term used to describe swallowing disorders. The most obvious signs of swallowing problems are coughing and choking; these issues can occur during or after eating or drinking. Other symptoms may include difficulty chewing, slower eating, avoidance of certain foods, drooling, fatigue with eating, and difficulty starting the swallow. Some subtle problems, when identified early, can be effectively managed.

How can people with Parkinson's be proactive in maintaining their ability to communicate & swallow?

Communication and swallowing changes are among the first motor symptoms identified by people with PD – sometimes even before they have been seen by their general practitioner or a neurologist. With over 80% of people with PD experiencing some degree

of communication and swallowing problems, the most proactive thing people with PD can do is see a Registered Speech-Language Pathologist (RSLP) who has experience working with Parkinson's clients.

I cannot stress enough: the earlier, the better for evaluation and treatment as it will help maintain quality of life. Although you do not need a referral to see an RSLP in BC, it is important that your team of healthcare professionals work together and know what you are pursuing for your care. Talk to your physician or neurologist about the importance of early contact with an RSLP.

What are some self-management strategies for strengthening communication & ensuring safety when swallowing?

Following evaluation by an RSLP, exercises and strategies can be introduced to improve communication and swallowing.

Another option is the Lee Silverman Voice Treatment® (LSVT®), which is an evidenced-based voice therapy for people with PD. It runs 4 times per day for 4 weeks. During the program, regular home voice exercises are established to be maintained after the sessions with the Speech-Language Pathologist are completed. Since this is most often a service offered through private practice, I understand it is not attainable or realistic for most.

We started the Communication & Swallow Workshops to introduce people to voice exercises they can incorporate into their routine at home. This was not intended to take the place of contact with an RSLP. Instead, I do introduce some voice and swallowing exercises that people can start before they see a professional.

In the workshops, I discuss swallowing evaluation, exercises, and strategies. The tricky thing here is that not everything works for everybody, and, in some cases, a strategy that helps one person may cause risk for another. It is very important that people with PD are referred for a comprehensive swallowing evaluation so that we know exactly what to recommend.

How can carepartners help people with Parkinson's maintain their communication & swallowing abilities?

Carepartners are an important member of the team for support, love, encouragement, and transportation. Sensory proprioception, your brain's ability to know

what your body is doing, is impaired in PD. This means the person with PD doesn't always have awareness of how they are moving through their day. They may need a reminder to perform exercises and use strategies that have been recommended to improve communication and swallowing. Education about PD is as important for the carepartner as it is for the person with PD. Every member of the healthcare team should be willing to learn about PD and, most importantly, learn from each other.

How do speech-language pathologists treat advancing symptoms of communication & swallowing?

Communication and swallowing problems do not necessarily progress from mild to severe in Parkinson disease. Someone may have mild problems throughout their journey, some may start with more severe problems, or some may see symptoms worsen with disease progression. I always start with exercises and strategies before recommending more significant changes such as changing texture of food and drink, a feeding tube, or using an augmentative communication system, such as a picture or alphabet board, or text-to-talk software. We would really like to be able to avoid such dramatic solutions. This is another reason to support early contact with an RSLP.

What can someone expect from attending a Communication & Swallow Workshop?

Knowledge is power. One of our goals in providing these workshops is to help people with PD and their carepartners understand issues related to communication and swallowing problems with Parkinson's disease. Historically, only 3-4% of people with PD have pursued evaluation and treatment with an RSLP. These workshops provide us with the ability to educate, and connect people with the support they need to maintain quality of life.

Are there any technological tools people can use for communication & swallowing issues?

The question I get asked the most is about a personal amplifier. I am not a huge fan of this in general for people with PD. This tool only amplifies what you have – it does not make you better. If the only concern is low vocal volume, it might be helpful, but if there are other changes to voice quality, articulation, or rate of speech, the amplifier will simply make all of that louder.

DID YOU KNOW...

If there are no LSVT® certified professionals in your area, you can encourage your local speech, physical, or occupational therapists to become certified. Online training takes as little as two days.

There are a few tools out there that may be helpful. An expiratory muscle strength trainer can help strengthen muscles needed for voice, swallowing, and coughing. A strong cough is important for swallowing safety. The stronger your expiratory muscles, the better. Delayed auditory feedback through a device can also be effective for some people with PD in improving fluency of voice and speech.

As with any new therapy, pursue these tools with the support of an RSLP. Using devices that are not helpful can cause unnecessary frustration and waste valuable time that could be spent utilizing more effective tools, exercises, and strategies.

Any closing words or advice for people with Parkinson's and their carepartners?

The PD community is one of the most proactive groups of people I have worked with over the years. From researchers to people with PD and carepartners, I consistently witness people pursuing opportunities for improvement and education. Stay positive and take advantage of all that is out there to help you get up and moving every day. Learn and do.

Additional Resources

If you have any questions related to communication and swallowing with Parkinson's disease, you can reach out to Sherri at the Surrey Voice Clinic.

Surrey Voice Clinic | bit.ly/surreyvoiceclinic
sherri@surreyvoiceclinic.com | 778-574-2747

To find a Registered Speech-Language Pathologist in your area, use the following resources:

Speech & Hearing BC
www.speechandhearingbc.ca | 1-877-222-7572

College of Speech & Hearing Professionals
www.cshhpb.org | 604-568-1568

Lee Silverman Voice Treatment® Global
www.lsvtglobal.com | 1-888-438-5788

ASK AN EXPERT



Kathleen Yue Discusses Palliative Care for Parkinson's

Palliative care is intended to provide medical services, emotional support, and spiritual resources for people with incurable and degenerative diseases, and those who are close to death

(HealthLink BC, 2017). A palliative approach to care focuses on comfort and quality of life instead of, or alongside, intensive and invasive treatments aimed at curing chronic diseases. It involves the entire healthcare team, as well as social workers, volunteers, and others who support the person receiving care with non-medical tasks, such as emotional support and guidance, running errands, and advance care planning.

The BC Centre for Palliative Care (CPC) works with the Ministry of Health in BC, as well as national committees, healthcare organizations and non-profits, to promote best practices in palliative care.

Kathleen Yue, RN, BSN, MN, CHPCN (C), is the Clinical Lead, Education at the BC CPC. She works to educate healthcare professionals on how to best support their clients and families by adopting a palliative approach to their specific field of care.

What is the palliative approach?

You may be familiar with palliative units in acute care hospitals, or hospice care with a home-like environment; but palliative care is really a philosophy, rather than a place. The philosophy of palliative or hospice care focuses on quality of life, comfort, and living well. It is person and family-centred, so your values, beliefs, and priorities are an important part of your care.

Palliative care used to be a specialty offered only near the end of life, particularly for those with terminal cancer. Today, we focus on a palliative approach for any type of care. The focus is on trying to help anyone who has a life-limiting illness, from

the time of diagnosis. Parkinson's is life-limiting in that it is incurable, progressive, and affects all aspects of your life.

Often, people will say, "I don't want to talk about palliative care. I don't want to go there right now."

When things get worse, it can be a much more difficult conversation. The best time to talk about things that could happen in the future is before a crisis occurs when you are still calm.

There are many issues that can arise with advancing Parkinson's. A palliative approach is holistic, supportive, team-based, and focused on your priorities – the main message is that you are not alone. Advancing symptoms can be scary, but there are many people around to help you.

Why choose palliative care?

When I worked in the hospital, there was a clear distinction between curative and palliative care. I noticed that when the focus changed to palliative care, the whole atmosphere around the patient, family, and healthcare team completely changed. The anxiety levels went down, in general, and I really felt a marked difference in the approach to care.

In light of growing support for Medical Assistance in Dying, there has also been a renewed focus on palliative care, helping people to live comfortably and have a high quality of life, regardless of their diagnosis. All care should really be that way.

What kinds of services are provided?

Most healthcare involves a team, but this is especially true in palliative care. The healthcare team members involved in palliative care include physicians, pharmacists, physiotherapists, occupational therapists, dieticians, home support workers, case managers, counsellors, spiritual health practitioners, social workers, and more. Each person on the team brings a toolbox of knowledge and resources.

Your healthcare team can help you with advance care planning, assessments of your health, safety, and wellbeing, equipment to assist you with daily living, symptom management tools and strategies, and social and spiritual support.

PALLIATIVE CARE SERVICES:

- medical services with a holistic approach (i.e., involving the entire healthcare team, or accommodating alternative treatments)
- emotional support resources (counselling, spiritual support, etc.)
- advance care planning (with doctors, case managers, family, etc.)
- hospice care, residential/long-term care facilities, palliative care units in hospital
- safety support services (i.e., home safety assessments by home & community care workers/volunteers)
- support for carepartners and family (all services above, in collaboration with carepartners/family, or with consideration to their needs, as well as respite care)

What is the role of advance care planning in the palliative care approach?

Upon diagnosis, many recognize that their time is, or may be, limited by their illness. Some people have told me that when they have a life-limiting diagnosis, part of it can be a gift, because all of the unimportant things in life fall away, and you can really begin to think about what matters most to you, and how you want to spend your time.

Every choice we make in life is a balancing act. This does not apply only to major choices, like those about CPR or Do Not Resuscitate orders, but involves thinking about everything, like where you want to live, who will care for you, and how you will communicate if you are unable to do so verbally.

In advance care planning, legal documents are helpful only because they are part of a conversation. You cannot predict what things are going to be like for you, or what you might want to do in certain situations. Talking about end-of-life decisions with those who are close to you is the most important part of advance care planning. Share with your family and health care team your values, beliefs and priorities.

People with Parkinson's do need some help with their daily living, and if people are wanting to stay

home until the very end, it is a family commitment, and sometimes a financial one. Some people love the idea of being able to give that gift to their loved ones, so the benefit of caring for their family outweighs the cost that might be taking time from work, for example.

Many people do prefer to stay at home until their death, but most die in residential care or acute care. Usually, when people end up dying in acute care, it is because there has not been planning ahead of time. Planning with your physician is important to avoid dying in acute care. Many physicians say they would love for their patients to make separate appointments to talk about advance care planning, so the discussion is more focused. So, go ahead and make that appointment, and let your doctor know what is important to you, because they will likely be consulted in the future.

How can I ensure my healthcare team is making the right decisions for me?

We recommend that you keep a diary for all of your symptoms. What can help your healthcare team make informed decisions is to have a really good assessment, and a full picture of your symptoms.

The BC CPC Symptom Management Guidelines include a mnemonic – **OPQRSTUV** – that you can use in your diary to help you track your symptoms:

Onset: *When did you first notice this symptom?*

Provoking & Palliating: *What makes this symptom worse and better?*

Quality: *How does the symptom feel? (e.g., different types of pain, like aching or tingling, can have different causes and treatments)*

Radiation: *Has the symptom travelled or spread anywhere else?*

Severity: *How severe is the symptom? Rank it on a scale of 1-10.*

Treatment: *What helps you manage the symptom, or makes it go away?*

Understanding: *What is your understanding of the symptom and its implications?*

Values: *How does this symptom impact your life? How would you like to treat it?*

CONTINUED ON PAGE 15...

CELEBRATING 50 YEARS OF COMMUNITY

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.

Parkinson Society BC invites 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.

We will continue to grow our online resources, like webinars, online support groups, and educational materials, to reach those affected by Parkinson's across the province.

In 2019, we are celebrating you! Throughout the year, we will be sharing the stories of those touched by Parkinson's to increase public awareness, and honour the strength of our community.

Since its inception, the Society has relied on the generous support of our volunteers, who help improve the lives of people with Parkinson's in BC by raising funds, spreading awareness, and facilitating support groups. This January, we began sharing the stories of some of the volunteers at the heart of our community, in our monthly Good News e-newsletter. To read the stories published so far, visit www.parkinson.bc.ca/volunteer-profiles.

Beginning this April, we are also launching our very first video series, highlighting the Society's history and achievements, and the community that has helped us along this journey. This series is being produced with awareness in mind. We hope that these stories will resonate not only within our community, but inspire the public to support our mission to ensure all British Columbians touched by Parkinson's know that they are not alone on their journey.

WANT TO GET INVOLVED? TURN TO PAGE 16...



ANNIVERSARY

Parkinson Society British Columbia

1969

The British Columbia Parkinson's Disease Association (BCPDA) was incorporated as a non-profit society in 1969. The society was started by staff members of the Vancouver Neurological Centre, with a mission to address the specific needs of the local PD community.





2019

Today, we celebrate 50 years of service. Thanks to your support, we are that much closer to our goal of supporting each and every individual touched by Parkinson's in British Columbia.

2002

We changed our name to Parkinson Society British Columbia on September 14, 2002. At this time, we were one of the largest regional partners of a national federation of Parkinson's organizations, leading the way in the production of educational materials – which continues to be a strength of the Society today.

1989

For its first 20 years in service, the BCPDA was entirely led by volunteers. Our first paid staff member was Executive Director, Ellen Lefevre, hired in 1989. Ellen was our only staff person until 1992, when we hired a Support Services Worker.

SAVE THE DATE: MOVING FORWARD, TOGETHER

Our provincial conference is back this year, with a new stream for healthcare professionals. Speaker and session information coming soon. Stay tuned to our website for upcoming details.

October 26, 2019 | Vancouver

LIVING WELL

Oral Health & Hygiene

The symptoms of Parkinson's disease (PD) can present unique challenges in maintaining oral health and hygiene. Age-related dental problems can be especially difficult to manage for people with PD who may have difficulties with symptoms ranging from mobility issues to anxiety and apathy.

To date, studies of dental health in people with Parkinson's hold varying results. Some studies have found that people with PD are missing more teeth, and have more cavities than people without the disease; other studies suggest the opposite. Despite conflicting evidence, it is generally understood that, in most cases, Parkinson's does not negatively affect oral health, but rather one's ability to perform daily hygiene and self-management tasks that can, in turn, determine health outcomes.

A recent Brazilian study of people with Parkinson's used subjective means of measuring oral health, looking not only at dental problems, but also at chewing difficulties, denture discomfort, motor symptoms, and self-perception (Ribero et al., 2016). This study found that people with Parkinson's had the same age-related dental concerns as the control

group, though those with PD reported more negative self-perceptions of their oral health. This is likely due to the discomfort and difficulty of self-management caused by the motor symptoms of PD, and may additionally be tied to the increased anxiety and apathy present in people with Parkinson's.

Self-management

With adequate medication management, people with Parkinson's can maintain good oral health and hygiene, despite the challenges of motor symptoms like rigidity, tremor, and loss of manual dexterity. Here are some strategies to keep in mind:

- Whenever possible, perform your oral hygiene tasks during times when your medications are most effective.
- To get the most out of brushing your teeth, as well as to protecting your gums, brush for longer, rather than more vigorously.
- Electric toothbrushes and handle-style floss holders can help make it easier to brush and floss with a tremor.

Your dentist can help you create a personalized oral care plan, tailored to your needs. Parkinson's can increase the risk of dental decay and injury, depending on the symptoms you experience. For example, dyskinesia affecting the mouth may cause grinding or chipping of the teeth, while balance and mobility issues can increase fall risk, and with it, the risk of damage to your teeth. PD and its medications can also cause changes in your saliva production, or a dry mouth. It is important to discuss your unique symptoms with your dentist, and report any changes with each visit.

Non-motor symptoms may also affect your oral health in a more indirect way. It is important to note any cognitive changes, depression, anxiety, apathy, or impulse control problems when visiting the dentist. As noted by Ribero et al., these symptoms can affect your perception of your oral health. This may mean that you experience greater frustration and discomfort, which can make self-care and hygiene seem more difficult. If this subsequently results in an aversion to these tasks, your oral health can decline. Your dentist can



support you by providing easier options for oral care, such as prescription-strength topical fluoride and chlorhexidine brushes for greater tooth protection.

Oral care is especially important for those with late-stage PD. With disease progression, many people with PD can experience cognitive changes, speaking difficulties, and a lack of facial expression. With this, it can be extremely challenging to convey pain and discomfort. Parkinson's progression is nearly impossible to predict, and varies greatly between individuals, so consider involving your carepartner in your oral care routine early. They can help you detect any changes in your teeth, gums, and mouth, as well as your ability to perform daily brushing and flossing.

Outside the Dentist's Chair

While it is crucial to report all oral health concerns to your dentist, there are certain issues for which you may need to consult other healthcare professionals. Excessive dry mouth or decreased saliva production may be a complication of your medications, and should be discussed with your neurologist. Saliva is critical for oral health; it acts as an antibacterial agent, and protects your mouth by neutralizing acidic foods.

Conversely, if you experience excess saliva and drooling, along with symptoms including difficulty swallowing, a gurgly-sounding voice, or coughing when eating or drinking, you may also need referral to a Speech-Language Pathologist. Difficulties swallowing cannot be addressed by your dentist, though they may be able to suggest certain changes to your diet, such as the consistency of food and fluid, which can make it easier to swallow.

Anxiety and Phobia

Phobia of dentists and dental work is extremely common, and can be brought about or worsened by the anxiety caused by PD. Some concerns include the fear of possible pain, needles, or restraint; feelings of helplessness or loss of control; embarrassment about your oral health; or anxiety about the cost of care (Bottger & Seltzer, 2018). If you share any of these concerns, it is important to remember that dentists are specially trained to ensure patient comfort and safety, and in most cases, there is no dental or oral problem they are unprepared to treat.

Planning and preparing for your dental appointments can make a difference in your overall comfort. Consider the following:

- If you need multiple interventions, book several short appointments, rather than a single long one.
- Plan appointments around your medication on-times.
- Use the washroom prior to your appointment.
- Ask if medications used during the treatment could adversely interact with PD medication.
- Find and agree upon signals with your dentist, that will indicate if you are uncomfortable, and to what degree. Be sure to have a signal for an emergency.
- If you have a tremor that affects your jaw or mouth, discuss the possible use of conscious sedation.
- At the completion of the procedure, sit up slowly and carefully, remaining seated for several minutes if necessary. Let your dentist know that you may need extra time to leave the chair.

Anxiety is known to exacerbate the symptoms of PD. Allow yourself enough time in the waiting room to recuperate after your appointment. Tell the receptionist in advance that you may do this.

Sources

Bottger, K., Seltzer, L.F. (2018). *How to Overcome Dental Anxiety*. Psychology Today. Retrieved from <https://www.psychologytoday.com/ca/blog/evolution-the-self/201802/how-overcome-dental-anxiety>

Riberio, G.R., Campos, C.H., Garcia, R.C.G. (2016). *Oral Health in Elders with Parkinson's Disease*. Brazilian Dental Journal 27(3). 340-344. Retrieved from <http://dx.doi.org/10.1590/0103-6440201600881>

Additional Resources

For more information on oral and dental care, anxiety management, and making the most of your dental appointments, take a look at some of our helpsheets:

Dental Care for Parkinson's Disease
bit.ly/pddentalcare

Depression and Anxiety
bit.ly/pddepressionanxiety

Effective Communication with Your Healthcare Team
bit.ly/paceframework

Preparing for a Medical Appointment
bit.ly/pdappointmentprep

CAREPARTNER'S CORNER

Family First, at Every Stage

Whether you are a spouse, family member or close friend, no one is prepared to become a carepartner. Adjusting to this role can be difficult and requires mutual vulnerability and support between the person with Parkinson's disease (PD) and their loved one. This is true at all stages of disease progression, including when transitioning into more involved caregiving roles. Open communication, compassion, and understanding, from both the carepartner and the person with PD, can make this transition easier.

Rebecca Gifford and Pat Mauch are two carepartners in very different places along the journey, though they share an important thing in common: they do not let terms like carepartner or caregiver define them, or their relationships with their spouses. Their stories remind us that family comes first.

Rebecca Gifford

Rebecca Gifford is a freelance writer and workshop facilitator, and homeschools her nine-year-old son, Henry. Rebecca's husband, Larry, still works full-time, even alongside running his own podcast, *When Life Gives You Parkinson's*. To outsiders, the Giffords' family life looks very much like it did before Parkinson's; together, they explore the outdoors, go to farmers' markets, and swim at their local community centre. It has been just under two years since Larry was diagnosed, and the family is still adjusting.

How did your journey as a carepartner begin?

Our whole family recognized that Larry's body was responding and functioning differently in the couple of years before diagnosis. He was walking with a pretty consistent clomp and dragging his right foot. His hand began shaking when he tried to do certain things like pick up a glass or pass an item to someone. In retrospect, there were other clues — a softening of his facial features, a dampening of his normal exuberance and enthusiasm — but we didn't know these were potential symptoms of Parkinson's until after the diagnosis. It's amazing what we and so many of our

loved ones didn't know about Parkinson's before we had to. Who knows how many people are showing signs of early PD without even being aware.

What does everyday life as a carepartner look like?

Right now, being a carepartner means a lot of little things. On a practical basis, it's things like doing most of the driving, because Larry's reaction times are slower, and most of the cooking because Larry has lost most of his sense of smell and doesn't enjoy it like he used to. I make sure we, as a family, remember the details and minutiae of our life because Larry has more trouble juggling too many things in his head.

He really doesn't need a lot of physical or practical care support yet. So, my role as his main emotional support is how I fulfill my carepartner "duties" right now. Mostly, I simply make sure he knows I am there as a present and loving partner, no matter what. I can't guarantee my mood will be sparkling or that I will react how he wants me to. Neither can he. But as with the rest of our marriage, we are committed to supporting each other on our journey, wherever it may take us. That's what I can offer him right now: someone to walk (or clomp), sit, talk, laugh, cry, and just be with him.

How are things different today, compared to when your partner was first diagnosed?

When Larry was diagnosed, there was a sense of relief, believe it or not. But as we learned more about Parkinson's and its progression, not to mention the very long list of potential symptoms, the uncertainty of the journey ahead of us all hit me. For a while, it became terrifying and sad to think about the future. At first, I was in shock a bit, and simply trying to maintain any sense of stability for myself, my husband, and especially our son. I wanted to give Larry some space to deal with all that he was faced with, and it became easy to deny and push off what I needed to look at. But then the reality of the situation and all that PD permeates on a daily basis became very clear very quickly. I went through a few difficult months where I grieved my pre-PD husband and my pre-PD life. I believe I still am to some extent, and may continue to as the disease progresses, but I've moved through much of that, and I'm as ready as I can be to move forward in our new normal.



Rebecca &
Larry Gifford

What do you wish others knew about being a carepartner?

I wish that others were more aware that being a spouse or partner of someone with YOPD is surprisingly lonely. There aren't a lot of us out there. Even though I have a fantastic network of friends and family, it is difficult to find folks who can hear, and empathize with every aspect of this experience.

Because our support circle is still so surprised, confused, and sad for us as a family, they are only beginning to find a way to be with us without feeling badly for us or feeling the fear or pain that comes up when seeing someone relatively young struggling

with their body and life in this way. So, I suppose what I wish people would understand is that we are aware it's difficult to witness what our family is going through at times and to adapt so quickly to the shifts when you're not used to it. We never want anyone to ignore that reality, and we completely empathize. We also know that because of this the people around us often don't know what to say, and I would reassure them that there's no "right" or "wrong" way to respond. An honest, authentic response is always appreciated, no matter what that may be.

What advice do you have for new carepartners, or the family and spouses of newly diagnosed individuals?

For those supporting newly diagnosed individuals, I would say: Be gentle with yourself. There is a lot to take in and the changes will come at you fast. Everyone will react differently to this new life and strange journey. At some point, you likely will feel or behave in ways you may be compelled to judge yourself for.

Be easy on yourself. Forgive yourself. Offer love to yourself just as much, if not more, than you offer it to the dear one you are supporting. Know that you are a complicated, beautifully imperfect human being going through something extraordinarily difficult. Let yourself be beautifully imperfect. There is great courage in your vulnerability, in acknowledging that you're going through something big, and in letting yourself move through it in your own way and at your own pace.

What are you learning from being a carepartner?

I am reminded each day that I get to spend with my dear family that there is so much richness in our life now. Most of the time, it's an easy choice. Do we get scared and overwhelmed? Of course. But even in the short time PD has been in our life, we've learned that dwelling there is a recipe for living in fear rather than enjoying and thriving in this beautiful life we've created together.

What does self-care look like for you?

I meditate regularly. Meditation makes a world of difference, because it may be the only time all day you allow yourself to just be however you showed up that day. And as it becomes more a part of your life, that space, clarity, and balance is easier to access when you're not sitting silently in a quiet room.

Time outdoors is very relaxing and healing for me, as is exercise. So, I often combine them and walk or hike. I was a massage therapist for several years, so I know the importance of good quality bodywork to maintain a sense of wellness and balance. It's an excellent way to feel cared for in a situation where you likely often feel like you're caring for others all the time.

As a writer, but really just as a human, creative expression is important for my own well-being. It's yet another tool that helps many people deal with life's challenges. I fully expect that as my role as a carepartner evolves, my self-care tools and rituals will need to evolve, as well. This is what works for me right now.

CONTINUE TO PAT MAUCH'S
INTERVIEW ON PAGE 14...

Pat Mauch

Pat Mauch is a retired Public Health Nurse, who worked mainly with children, teenagers, families, and in schools. Pat has been a lifetime volunteer at whatever stage her life was and continues in the Parkinson's domain. Today, she enjoys her many hobbies, including volunteering, gardening, reading, and bridge. Her husband, George, has had Parkinson's for 20 years, and in this time, the pair have become prominent members of their local PD community. They have never let Parkinson's stand in their way.

How did your journey as a carepartner begin?

My husband, George, has had a Parkinson's diagnosis for 20 years. Our life did not change for many years – we still did all our usual activities, and with retirement increased our travel, which we continued until this year. We did anticipate that some changes would come so we continued to work on our bucket list. My bigger role as a more involved carepartner started about one year ago.

What does everyday life as a carepartner look like?

My role has expanded to manage most household affairs, and to help my partner take his medication on time, make appointments, and fit in his exercise activities. Serving as a social secretary with family and friends has become an important role as well. Being the facilitator for a Parkinson's Support Group takes a lot of my time, but is a very rewarding and humbling experience.

How are things different today, compared to when your partner was first diagnosed?

The first 19 years were not that much different and we made the adjustments to our lifestyle that were required and carried on well. Everything changed very quickly once the non-motor aspects of PD started showing, changing some of his activities and abilities. We made some practical decisions before some of the issues became a problem. We downsized from a house to a condo probably earlier than we would have and more recently sold our Gulf Island house that George built 40 years ago. Because he had always been very physically active, exercise has been the easy part of treatment for him, and has helped him to manage the motor parts of the disease. The non-



Pat & George Mauch

motor aspects are what is more difficult for him and therefore for me. Our couples social life is also very different now - we have a less active social life. We are grateful we did all the things we did while we both could. Now we make different choices and choose different activities, as many older folks do.

What have you learned from being a carepartner over the years?

Now, with advanced PD, changes are happening faster. Looking back, I think the most important thing is that we just took it one step at a time, while knowing as much as we could about the stage we were involved with. We did not worry about the future until it came, while still learning about the disease's progression. No two people with Parkinson's are the same, so you have to go your own road, in many ways. Enjoy the good moments and do not dwell on the difficult ones.

What does self-care look like for you?

Self-care always sounds so easy, but is not, for many people. Gardening and being outdoors has always been like meditation for me. Being social is also important to me, so I volunteer in the travel world, continue to play bridge, and participate in a book club. Luckily, my husband can still come to the gym with me, so we both benefit from this activity. We also both like going for long walks, so we do that together, which is another benefit for both – exercise and being outdoors.

What do you wish others knew about being a carepartner?

Sometimes, it can be difficult to share your concerns and challenging issues with others, as you don't want to be complaining about your partner to mutual friends and family. They did not choose to have this condition, and it is important to maintain their sense

of self-worth. The rewarding aspects are seeing them enjoying life as much as possible, and still being able to do things that you can share together. Carepartners have to plan for their own future as well as do advanced care planning for their partner and also prepare for the “what if” something happened to me.

What advice do you have for new carepartners, or the family and spouses of newly diagnosed individuals?

I had watched others who were carepartners for other conditions, so I had some information about what to expect as well as working in the medical field. We decided to start work on our bucket list

as soon as we received the diagnosis. We were kayaking in Belize 3 months later, and continued to keep our travelling and social agenda very active. My advice is to keep as informed as possible and be proactive with the use of all available healthcare resources. I also strongly recommend both partners be part of a support group to learn from others with PD and their carepartners. Keep involved with all your different support groups – family, friends, medical resources and local Parkinson’s groups.

Postpone nothing! Do everything you want to do as a couple and as a family while you can!

ASK THE EXPERT: PALLIATIVE CARE FOR PARKINSON’S CONT’D

How can I support myself and my loved ones?

Self-management is a significant part of palliative care. To support yourself and your carepartners, consider alternative strategies for treating your own pain and fatigue that do not involve a trip to your physician.

In palliative care, we talk a lot about total pain; that is referring to areas of life that could be increasing your pain. For example, if someone has pain from a fractured leg, and they are feeling guilty that they caused an accident that put them in that position, they will have more pain because of that guilt. What this is really saying is that pain is not only physical. That is why it is important to pay attention to what else is going on in your life, and to share all of that with your healthcare team. There are a lot of different things you can do for total pain – medication is not the only option for treating pain.

For fatigue, one metaphor I have found extremely helpful is the energy bank. This will help you consider what depletes your energy, and what increases it. So, with each activity you are considering, you can think about what it will cost you from your energy bank, or how much it will deposit into it. Research has found that, sometimes, too much rest can actually make your fatigue worse. Instead, you can think about energy restoration activities. Some people find meditation, listening to music, or crafts, can increase your energy more than rest.

You should also plan for assistance, and adapt your expectations. Say that bathing and dressing takes up all of your energy for the day, but your grandchildren are coming by in the afternoon. Maybe you do not want to deplete your whole energy bank by the time they arrive, so you call in a home care worker to help you have a bath, so you have more energy for your grandchildren. Again, these decisions are all about what is most important to you.

Sources

HealthLink BC. *Hospice Palliative Care*. Retrieved from: www.healthlinkbc.ca/health-topics/aa114690

Additional Resources

Advance care planning is integral to a person-centred palliative approach. The BC CPC website offers information and resources on advance care planning to support individuals with life-altering conditions in making important decisions about their end-of-life care.

BC Centre for Palliative Care | www.bc-cpc.ca/cpc/acp

Contact your local health authority for more information on palliative care, home and community care services, and advance care planning.

Fraser Health | www.fraserhealth.ca

Interior Health | www.interiorhealth.ca

Northern Health | www.northernhealth.ca

Vancouver Coastal Health | www.vch.ca

Vancouver Island Health | www.islandhealth.ca

APRIL IS PARKINSON'S AWARENESS MONTH



ANNIVERSARY

Parkinson Society British Columbia

THE CAMPAIGN

This year, Parkinson Society British Columbia celebrates **50 years of service**. Since 1969, we have served to empower the Parkinson's community through providing resources and services to enable self-management, self-reliance, and self-advocacy.

April Awareness Month is an opportunity to engage the public in expanding their understanding of Parkinson's disease, and the diversity of our community.

This year's campaign highlights:

- Inspirational **stories** from people with PD, their families, and carepartners.
- The **history** of Parkinson Society BC, and the growth of our programs & services.
- Our Society's **mission** to ensure all British Columbians living with PD know that they are not alone on their journey.

GET INVOLVED

Let others know that April is Parkinson's Awareness Month, and use the hashtag **#PDANDME** on social media to tell your story.

Be sure to follow the Society online, and tag us in your April Awareness Month posts:

Facebook & Youtube: @ParkinsonSocietyBritishColumbia

Instagram & Twitter: @ParkinsonsBC

For our 50th anniversary campaign, we are building a timeline of the Society's history – and we need your help. Send in your photos from education events or fundraisers you have attended over the years for your chance to be featured.

Every journey with PD is unique, and we want to hear about yours. Be an ambassador for our awareness efforts, and have your story shared in our newsletters, on our website, or as part of our 50th anniversary video series. For more information, contact Jovana Vranic at jvranic@parkinson.bc.ca.

Pictured:

**Hilary, 27 | White Rock
Diagnosed with YOPD**

#PDANDME

WWW.PARKINSON.BC.CA/AWARENESS

NEWSWORTHY

UPCOMING EDUCATION EVENTS

Communication & Swallow Workshop, Quesnel & Prince George

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: Friday, May 10
Time: 10:00am - 2:30pm
Location: Royal Canadian Legion Branch 94
262 Kinchant St., Quesnel

Date: Saturday, May 11
Time: 10:00am - 2:30pm
Location: Spruce Capital Senior's Rec. Centre
3701 Rainbow Dr., Prince George

Cost: Member \$25 | Pair \$40
Non-member \$35 | Pair \$60

Regional Conference, Kelowna

Parkinson's disease is a unique and complex condition. To assist in expanding your knowledge of the disease, on June 22, Parkinson Society BC will host an afternoon of learning in 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.

Speakers will be announced soon.

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

UPCOMING WEBINARS

Ask the Expert: The Ins & Outs of PD Medication

The Pharmacists Clinic at UBC is Canada's first university-affiliated, licensed, pharmacist-led patient care clinic. They provide health consultation services to patients, research opportunities for the healthcare community, and learning opportunities for health professionals and students alike.

On April 23, the Pharmacists Clinic will be offering a webinar that will briefly discuss Parkinson's disease, medications, natural products, and other considerations that are associated with Parkinson's medications.

We welcome all individuals with Parkinson's to this webinar as well as their spouses and/or carepartners/caregivers, as they may benefit from learning more about the disease to assist in supporting their loved one.

Date: Tuesday, April 23
Time: 10:00am - 11:00am
Cost: Free

Ask the Expert: Balance & Falls

On May 21, Eveline Pasman, PhD Candidate at the University of British Columbia in the School of Kinesiology, will join Parkinson Society BC for the first time to share her research on postural instability in people with Parkinson's disease.

Date: Tuesday, May 21
Time: 10:00am - 11:00am
Cost: Free

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

New! Webinar Registration Waitlists

Due to the growing popularity of our webinars, online registration has been filling up fast! To help accommodate more participants, we have now begun opening waitlists for webinars when registration is full. We still recommend registering early to reserve your spot, as webinar capacity is limited. If you do not log in to attend your webinar, your space will be offered to the next person on the waitlist. For more information, email us at info@parkinson.bc.ca.



Ex Nihilo Vineyards cheque presentation with members of our Kelowna support group.

**Do you like our new look?
We're taking it online!**

Champions for Parkinson's

On our Champions for Parkinson's campaign website, event organizers can set up their fundraisers with a personalized page where donors can make secure online donations using their credit cards. Our new sleek website design will make your fundraising story stand out, and will feature easier ways to thank your donors with a user-friendly email centre!

Parkinson SuperWalk

We want to support our SuperWalk participants by providing easy access to resources, and simpler methods for collecting donations, organizing teams, and sending emails. The new SuperWalk BC website is easy to navigate, so you can find and support your local walkers without hassle, and manage your fundraising page with a more user-friendly participant centre. Walkers can also collect badges for their fundraising pages, to recognize milestones like reaching team fundraising goals, or hitting SuperStar walker status.

If you have any questions or feedback, please let us know at events@parkinson.bc.ca.

SAVE THE DATE: PARKINSON SUPERWALK 2019

Registration opens April 4th. Sign up and make a pledge on our new website!

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

Thank you to our fundraisers & donors!

Shifting Gears

Last fall marked the end of Lois Leslie and Paul Gully's transcontinental bicycle ride! The pair rode through Europe, East Asia, Australia, and New Zealand, in honour of their dear friend, Marg deGrace, who passed away during their travels. The fundraiser brought in over \$15,000!

Fall Harvest Dinner

Thank you to Ex Nihilo Vineyards for an amazing \$19,155 raised at their beautiful dinner, auction, and concert! Ex Nihilo Vineyard's partners, Jeff Harder and Janet Azhadi, chose to support us because both of their fathers were diagnosed with PD. We are grateful for their generosity!

Champions for Parkinson's Raffle

The 2018 Fall raffle raised \$660. Our grand prize winner, Sharon Cizmar, won a \$500 Travel Credit Voucher from VIA Rail, and Pat Rupper took home the secondary prize of a Keurig® K200 Plus Series and pod starter pack. Congratulations!

Additional thanks to...

- **The Maathar Sangam Educational and Cultural Society of BC** made a donation of \$1,000 last year, collected at their golf tournament and walk-a-thon.
- **Paladin Labs Inc.** awarded the Society a \$5,000 unrestricted grant last winter.

Party for Parky

Last September, Tess Elia put on a 60s-themed dinner and dance party, catered by the Vancouver Portuguese Club. The night brought in \$590. Thank you, Tess!

#BeerParky Pub Night

TeaParky founder, Michael Cheung, put on a pub night at the St. Regis Bar & Grill. #BeerParky 2018 brought in \$1,333 through a silent auction, 50-50 raffle, and karaoke!

Pancakes & Churros for Parkinson's

Parkinson's and Alzheimer's Targeted Hope and Support, or Project PATHS, is a student-led initiative to raise awareness and funds for common neurodegenerative disorders. Throughout 2018, they raised \$400 with pancake and churro sales at the University of British Columbia Vancouver campus!

Fall Online Auction

Our Fall 2018 online auction was full of incredible items, from a weeklong cruise for two on the Holland America Line, to golf packages, and winery tours. Sales from the auction raised over \$5,000!



ANNUAL GENERAL MEETING 2018

We invite you to join us for our Annual General Meeting on Saturday, April 13, featuring guest speaker Dr. Matthew Farrer, UBC Professor of Medical Genetics, Canada Excellence Research Laureate in Applied Neurogenetics, and the Don Rix BC Leadership Chair in Genetic Medicine. Dr. Farrer is leading a global effort to discover new genes for Parkinson's and to accelerate the translation of these discoveries into new disease-modifying therapies. His lab has played a leading role in the discovery of every causal gene for typical late-onset Parkinson's disease, and he has also identified some of the genes for atypical and early onset forms of parkinsonism.

Following the meeting, Dr. Farrer will speak to his journey developing Parkinson's research and his hope for new discoveries in the near future. You will also hear from Larry Gifford, who has Parkinson's disease, and has been through genetic testing, as well as his wife and carepartner, Rebecca.

Light refreshments will be served.

**REGISTER ONLINE AT:
WWW.PARKINSON.BC.CA/AGM2018**

Date: Saturday, April 13
Time: 9:45am – 12:00pm
(registration opens at 9:00am)
Location: Library Square Conference Centre
Alice MacKay Room
350 West Georgia Street, Vancouver
Cost: Free for members.
Non-members interested in attending must sign up to be a member of Parkinson Society BC and pay the \$25 annual membership fee.

**DR. MATTHEW FARRER
SPEAKER**

 **Parkinson Society
British Columbia**
600–890 West Pender Street
Vancouver, BC V6C 1J9



RETURN POSTAGE GUARANTEED
PORT DE RETOUR GARANTI