

VIEWPOINTS



Winter 2024

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Quarterly Newsletter
by Parkinson Society
British Columbia

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Your support is essential.

Parkinson Society BC would not exist without the support of our members, donors, and volunteers.

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.

Here are a few of the ways you can support the 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.

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

SUPPORT GROUPS

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Ask An Expert

Yolanda Wang, Registered Dietician, discusses evidence-based nutrition for people with Parkinson's



Yolanda is a Registered Dietitian (RD) and an American College of Sports Medicine (ACSM) certified personal trainer. As a University of British Columbia (UBC) alumnus with a

Dietetics Major and Kinesiology Minor, she is passionate about working with clients to develop a healthy and satisfying lifestyle. She works on the research and program delivery side at the Brain Wellness Program (BWP) under the supervision of Dr. Silke Cresswell, providing nutrition education and cooking together with participants. Before joining the BC Brain Wellness team, she worked as a dietitian in acute care, gestational diabetes clinics, and long-term care facilities, and as a personal trainer at UBC Recreation Center. She is excited to introduce the nutrition piece to the comprehensive lifestyle and wellness projects at BWP.

Does diet impact either the symptoms or progression of Parkinson's disease (PD)? If so, how?

Diet or food behaviours could impact certain symptoms of Parkinson's disease, such as constipation, gas and bloating, fatigue, unintended weight loss, orthostatic hypotension (low blood pressure), and daytime sleepiness. This is done by adjusting the content, timing, and volume of food and drink depending on the specific issues the individual is facing. The considerations for content include fibre, fluid, caffeine, protein, fat etc.; the consideration for timing is mostly about scheduling the meals and snacks to avoid food-drug interaction, promote energy levels for daily activities and exercises, and promote recovery from exercises, etc.; as for food volume, it's usually about finding the appropriate volume to ensure adequate energy, while avoid causing nausea or low blood pressure.

This is not a one-way influence, as PD could also impact food behaviours and nutrition needs in various ways. This includes reducing the food intake due to hyposmia (decreased sense of smell), hypogeusia (decreased sense of taste), depression, difficulty chewing and swallowing, delayed gastric emptying, constipation, or dementia, as well as increasing or decreasing energy output due to tremor, bradykinesia, dyskinesia, or rigidity. The accessibility of nutritious food and the ability to prepare nutrition-adequate and enjoyable meals may also be impacted. Without proper management, this will in turn, further impact the symptoms and disease progression of PD.

There's currently no strong evidence from experimental studies supporting specific diets, food, or nutrients for the prevention or slower progression of Parkinson's, and thus, we cannot conclude what foods or diet will reduce the risk or progression rate of PD. However, several observational studies show the associations between certain dietary patterns, especially Mediterranean and MIND diet (combines the brain-healthy foods of the Mediterranean diet and the heart-healthy elements of the DASH diet, which was created to lower blood pressure), and reduced risk or severity of PD.

What role does inflammation play in Parkinson's, and how can diet help to reduce inflammation in the body?

The mechanism of PD development is not well understood. Experts and researchers have suggested the model of the gut-brain axis, where the disruption of the regular gut microbiome leads to local inflammation and increased gut permeability (leaky gut), which lead to systemic inflammation in the body and eventually cause neuroinflammation and neurodegeneration in the brain.

There is some indirect evidence to support the logic of the model, such as the altered gut microbiome composition, increased inflammation markers in blood circulation, and higher gastrointestinal comorbidities among people with PD. However, more research is needed to understand or prove the mechanisms.

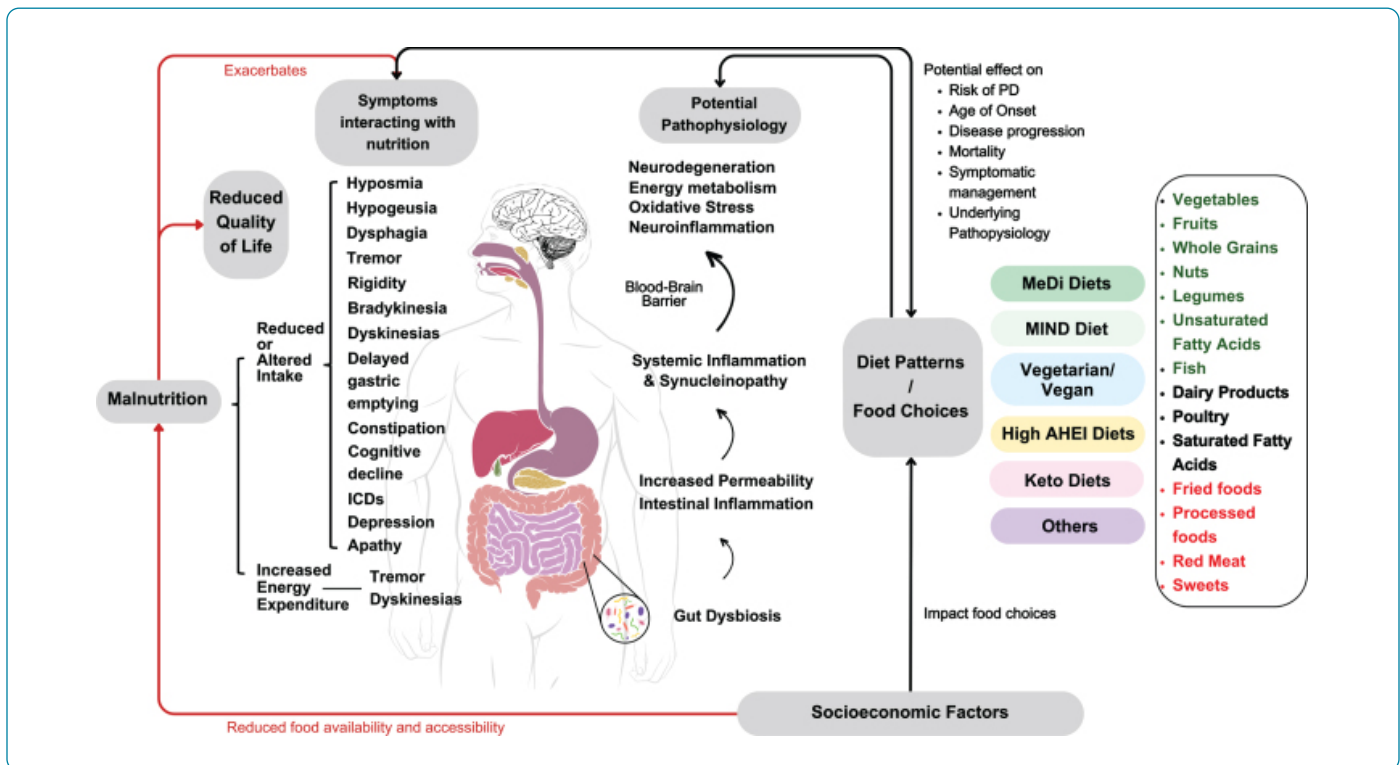


Figure 1. Summary of the complex interactions of dietary patterns and food choices with socioeconomic factors, PD-related malnutrition, disease pathophysiology, symptoms and quality of life. From Tosefsky, K. N., Zhu, J., Wang, Y. N., Lam, J. S. T., Cammalleri, A., & Appel-Cresswell, S. (2024). The role of diet in Parkinson's disease. *Journal of Parkinson's Disease*, 14 (Suppl. 1), S21–S34. <https://doi.org/10.3233/JPD-230264>

The current evidence on dietary patterns and PD (mentioned above) aligns with this model, as Mediterranean-style diets encourage the intake of foods high in anti-inflammatory components and discourage the intake of foods considered pro-inflammatory.

How does gut health influence Parkinson's, and are there specific dietary changes that can support a healthier gut microbiome for those with the disease?

Gut health may impact brain health through the gut-brain axis, the model mentioned above. Several studies have shown similar patterns of changes in microbiota among people with PD, which include the decrease of short-chain fatty acid-producing bacteria. Short-chain fatty acids (SCFA) play an important role in maintaining gut wall integrity. Decreased SCFA could contribute to increased gut permeability and inflammation in PD. The composition of gut microbiota was also shown to be related to certain PD symptoms, including consistency of bowel movement and constipation.

What is clear is that increased fibre intake, with proper hydration, can alleviate constipation, which may then improve nausea, low appetite, as well as medication absorption.

What is unclear (but is of interest), is the impact of dietary patterns, probiotics, or prebiotics on the composition of the gut microbiome, and its impact on PD.

Individuals with PD are advised to be careful about protein intake and medication timing. Can you explain why this is and what can be done to ensure they consume adequate protein throughout the day?

Our body uses similar mechanisms to absorb and deliver levodopa and protein. When taken around the same time, protein can impact the absorption and effectiveness of levodopa. Therefore, we usually recommend taking the levodopa-containing medication 30-60 minutes *BEFORE* a meal/snack with high protein, allowing the medication to be delivered to our brain or "kick-in", and 1.5-2 hours *AFTER* a high-protein meal, as a balanced meal usually takes longer to digest (compared to fast-

relieving medication). The length of these breaks may be longer or shorter depending on the individual's digestion and metabolic rate. I recommend my clients to experiment with it to see the best break length between medication and high-protein food.

Our protein needs vary. The general protein recommendation for most adults is 0.8 grams per kilogram of body weight. This is not individualized advice. The protein needs as we age may increase due to reduced absorption, certain chronic diseases, and to prevent muscle wasting, but they may decrease due to certain conditions, such as kidney disease. Please consult your healthcare provider if you have concerns about protein intake.

Most people can reach their protein needs by including protein-rich food in all their meals and having balanced meals, with protein food counting for ¼ of the volume (refer to Canada's Food Guide).

For people with low appetite or who take longer to digest/absorb meals, try **small frequent meals/snacks with protein** that range around medication time. For example, if I have levodopa every three hours at 7, 10, 13, 16, 19, and 22 o'clock, I can have small meals or large snacks at 8, 11, 14, 17, 20, and before bed if needed. This way, we can get consistent energy and protein intake without the stress of having a large volume of food/protein all at once.

People with motor fluctuations (medication does not work predictively and effectively) may benefit from a protein redistribution diet, where individuals eat low-protein meals during the daytime when they perform most of their daily activities and have a high protein intake during evening time to reach the protein requirement of the day. This is still an effective way to ensure proper protein intake.

Are there any popular diets (i.e. keto, Paleo, Mediterranean, plant-based/vegan) that people with Parkinson's should avoid?

From previous answers, we know that there's no strong evidence to support a specific dietary pattern in terms of reducing the risk of Parkinson's, apart from the general consensus on the Mediterranean, MIND diet, and diets with higher quality according to the Healthy Eating Index. These diets usually are high in fruit and vegetables, whole grains, plant-based protein, and healthy fat.

While they usually recommend reduced intake of certain foods, such as red meat, sweets, and fast foods, they do not require a complete restriction of certain food groups.

Like most dietitians, I won't recommend a client to go on a restrictive diet (a diet that eliminates one or multiple food groups) unless there is a large amount of evidence suggesting health benefits for the client's specific condition, or the client has personally tried and benefited significantly from the diet. When deciding whether to try such a diet or not, think about the risks versus benefits. What is the evidence supporting the benefits of a diet, and what are the risks associated with such a diet? For most of the restrictive diets, evidence of their benefits on PD is scarce.

There are a few studies showing potential benefits from following a ketogenic diet on the motor and non-motor symptoms, however, these studies were done on a small group of participants, with different study designs, and have different outcome focuses. Therefore, the benefits of a ketogenic diet are inconclusive. Some potential risks with restrictive diets in general include nutrition deficiency, weight loss, disordered eating, increased time commitment, and affected social well-being. Some people living with PD may already struggle with nutrition adequacy, weight maintenance, or stress management, so a restricted diet might not be a good option in these cases.

If someone is following such a diet, I highly recommend they work with their healthcare team to check nutrition adequacy regularly.

What tips do you have for dealing with loss of appetite in people with PD, due to either symptoms or medication?

Loss of appetite could be related to loss of smell or taste, reduced motility of the digestive system, nausea, apathy, depression, or increased difficulties with eating. Depending on the cause, one may try one or a few of the suggestions below to address the issue:

- **Find your motivation to eat**, either to get strength for your favourite exercise, to hang out with your family, to play with grandchildren, or to maintain your activities of daily living.

- **Explore the texture and presentation of the meals.** We love food for more than just the smell or taste. If food becomes “boring” to you due to the lack of taste, try to include various textures (crunchy, crispy, creamy, etc.) and colours, and play with it for plating.
- **Try ginger to alleviate the nausea.** You can put ginger in a ginger date smoothie or pour hot water over ginger slices, perhaps with lemon juice and honey, to make ginger lemon tea.
- **Have small frequent meals throughout the day.** With reduced motility of the digestive system, it may take longer to digest food, which can make you feel full easily and have no appetite for more. If you can't have a large amount in three meals, make it six small meals instead, and give your body time to digest before adding more in.
- **Choose high-energy foods** – especially those that are high in fat. Fat will provide more than double the energy of sugar or protein with the same amount of food. Therefore, if you get full easily or do not have the strength to eat more food, choose items such as nuts, seeds, nut butter or seed butter, avocado, vegetable oil, full-fat dairy instead of low-fat, or even ice cream! Some of these might not usually be considered “healthy”, however, if you are suffering from rapid weight loss, then these would be “healthier” for you than low-energy foods for weight maintenance purposes.
- **Try nourishing fluids**, such as smoothies, blended soup, milk or milk alternatives, and oral nutrition solutions (Boost or Ensure). If chewing takes too much effort, fluids might go down easier than solid food. Making sure you are getting the nutrients and energy you need from fluids is an efficient way to get both hydration and nutrition checked.
- **You can also try your favourite foods:** anything that you can eat works! This could be ice creams, chocolate, pudding, or mashed potatoes, etc.

Do you recommend any dietary supplements for people with Parkinson's? If so, which ones?

There's not enough evidence to support the general recommendation of vitamin or mineral supplements. This does not mean that no nutrition supplement will help. We just haven't found any. People may have heard or read anecdotal stories about how other people living with PD benefit from XX supplement.

It might be true for them, and it may or may not work for you. Again, I don't actively recommend any vitamin or mineral supplement, unless I know the person is deficient or at risk of deficiency, yet cannot meet the needs by food alone (food restriction, low food intake, impact absorption, etc.). In those cases, the supplement can be helpful and essential.

For other clients, if they have a supplement of interest, I would share the information I know on the supplement (or refer them to a pharmacist), explain any potential risk, and let them decide whether to try it or not. Some clients like to experiment on themselves with supplements; if it's within the safe dosage, and if purchasing the supplement does not cause a financial burden, then it is their personal choice, and I will not intervene. It is recommended to check with their doctor before taking any new supplement to avoid drug interactions.

Older adults may be at higher risk for certain nutrition deficiencies, such as vitamin B12, folate, vitamin D, iron, etc. If you suspect you may be at risk, ask your doctor for a relevant test. If the results show a deficiency or overload, work with your healthcare team to adjust your diet or supplement accordingly.

What are the best dietary strategies to help deal with fatigue and low energy levels that are often experienced by people with Parkinson's?

- **Snacks between meals** – eat every two to three hours for a consistent supply of energy (avoid protein around levodopa intake, still enjoy food with more sugar and fat – like fruit, crackers with creamy dip, etc.).
- **Adequate protein intake** to sustain muscle mass and maintain strength.
- **A moderate amount of caffeine as a central nervous system stimulant.** This may help with sleepiness during the day and increase workout performance if taken before exercise.
- **Simple sugar for a quick energy surge.** Although foods with complex carbohydrates (such as whole grains, fruits, and vegetables) are recommended for stable blood sugar and a consistent source of energy, there are times when we need a fast energy source, such as before an intense workout or during or after a long hike.

There are so many opinions about diet and nutrition, especially in our ever-connected digital world. How can people with Parkinson's ensure they are receiving high-quality, evidence-based information about this topic?

Look for reliable sources, such as government websites, relevant organizations, and people with valid credentials, such as registered dietitians.

You can also look for information that is backed up with peer-reviewed papers. However, this cannot guarantee that the information is not biased, as a lot of nutrition-related topics are controversial, and studies may have conflicting results. One paper may not tell you the whole truth.



Would you recommend people with PD work with a dietician? If so, how can they get connected to resources and dieticians in their community?

People who live with PD and have diet or nutrition-related issues or questions could benefit from talking to a dietitian. However, there are also many people living with PD who already have their own dietary routine that works really well for them and may not need a dietitian's consultation. If you are unsure, you are always welcome to talk to an RD and figure it out. You can also complete a validated nutrition screener

to see if you are at malnutrition risk (see the Screen-8 tool at <https://bit.ly/screen8tool> and the Screen-14 tool at <https://bit.ly/screen14tool>. Guides on how to use these tools may be found at <https://bit.ly/nutritioncreensguides>).

For free one-on-one nutrition counselling for people living with PD in BC from the BC Brain Wellness Program (self-referral form - priority given to those with higher nutrition risks), visit:

<https://bit.ly/BWPnutritioncounselling>

For group nutrition and cooking classes available for anyone living in BC who is interested, visit:

<https://bit.ly/BWPnutritionclasses>

Anything else you would like to add?

Everyone's journey is different, and their health and nutrition priorities can be very different too. I acknowledge that sometimes working with a dietitian alone cannot address the nutrition problem. Some people may need reminders to eat, others may have trouble chewing or swallowing, and some people may need extra support, time, or strength to prepare the meal. Many healthcare workers, including people at the Brain Wellness Program, hope to form a network and community that delivers person-centred, team-based care to work better together with people living with PD and caregivers.

I also want to acknowledge that food is not just about nutrition. It can be what brings people together, childhood memories, the treat of the day, and language of care. I hope this can be a reminder for whoever is reading this article to continue to connect, talk, share, and create memories over food!

ADDITIONAL RESOURCES & FURTHER READING

- **Older Adult Nutrition Screening**
Resources for Older Adults
<https://bit.ly/4ebhSAY>
- Rusch, C., Flanagan, R., Suh, H., & Subramanian, I. (2023). To restrict or not to restrict? Practical considerations for optimizing dietary protein interactions on levodopa absorption in Parkinson's disease. *NPJ Parkinson's Disease*, 9(1), 98.
<https://doi.org/10.1038/s41531-023-00541-w>

RESEARCH OPPORTUNITY FOR PEOPLE WITH PD: PD-DIET PILOT STUDY

You may be eligible to participate if you:

- Are between 40-80 years of age with a clinical diagnosis of PD,
- Are cognitively and medically stable,
- Have computer and internet access at home (with video capability),
- Can follow verbal & written instructions in English,
- Can complete an MRI scan (no contraindications).

Researchers at UBC are studying how diet impacts the gut microbiome and Parkinson's symptoms. This 18-month study includes biweekly group cooking classes and monthly individual sessions with a dietitian.

If interested, please contact:

PD.Diet@ubc.ca | 604-827-0576

Research

Cannabinoid compounds to augment L-DOPA treatment and prevent L-DOPA-induced dyskinesia

Dr. Ali Salahpour from the University of Toronto is investigating the potential of combining L-DOPA, the most effective drug therapy for Parkinson's disease (PD), with cannabinoid compounds to enhance treatment efficacy and reduce side effects. Long-term or high-dose use of L-DOPA often leads to L-DOPA-induced dyskinesia (LID), a significant and undesirable side effect characterized by uncontrollable, dance-like movements. The research aims to find out if cannabinoid compounds, which interact with the dopamine system affected in PD, can improve the effects of L-DOPA and reduce LID.

Preliminary results in animal models indicate that compounds acting on the cannabinoid system can enhance L-DOPA response. The current project systematically tests 11 different cannabinoid compounds for their potential to improve L-DOPA response and reduce LID. Success in this area could revolutionize PD treatment, providing substantial benefits by enhancing drug efficacy and reducing dyskinesia.

As a scientist working on the dopamine system, Dr. Salahpour is interested in Parkinson's, but is also working on rare diseases of the dopamine system, such as Dopamine Transporter Deficiency Syndrome, which is also called infantile parkinsonism-dystonia. As a pharmacologist, his goal is to try to find new drugs or treatments that could be beneficial for individuals with these diseases.

Source: Parkinson Canada Research Program.



RESEARCHER

Dr. Ali Salahpour
University of Toronto
Pilot Project Grant

FUNDING AMOUNT

Co-funded through a partnership between Parkinson Society British Columbia and the Parkinson Canada Research Program
\$75,000 over 2 years

Living Well

Sleep disturbances in Parkinson's

Sleep disturbances are a common and significant problem for individuals with Parkinson's disease (PD), sometimes greatly affecting quality of life. These issues often exacerbate the motor and non-motor symptoms of PD, creating a cycle of discomfort and fatigue. The causes are multifaceted, involving both the neurodegenerative processes of PD itself and the side effects of medications used to manage the condition. However, by understanding how these problems arise and what can be done about them, people with Parkinson's can improve their overall wellbeing and get a good night's sleep.

Causes of sleep disturbances

Multiple brain areas and neurotransmitters that are impacted by Parkinson's are involved in regulating sleep and wakefulness, which explains why sleep disorders are very prevalent amongst people with PD. In fact, one frequently-cited study found that up to 98% of people diagnosed with the disease had some form of sleeping problem, with 30% experiencing issues maintaining normal levels of alertness and wakefulness during the day (*Stefani & Högl, 2019*). Another study stated that individuals with Parkinson's disease averaged only five hours of sleep per night and experienced twice as many awakenings compared to age-matched individuals without the disease (*American Parkinson Disease Association, n.d.*).

Additionally, the medications used to treat PD can disturb sleep. In particular, the timing of dopaminergic medication seems to matter – one study found that taking it right before sleep resulted in less rapid eye movement (REM) sleep – the stage of sleep in which we dream (*Chahine et al., 2013*). This is problematic because the benefits of REM sleep include improved mood and memory, healthy brain development, protection against dementia, and a boost in problem-solving skills (*Levine, 2024*).

People with Parkinson's also experience a reduction in something called sleep spindles, which are short bursts of brain activity during non-REM sleep. While these bursts of activity have not always been understood, new research is emerging that shows they might be quite important in memory consolidation, learning, and protecting sleep from external disturbances by shutting off a part of the brain called the thalamus, which processes information from our senses. Reduced sleep spindles leave people with PD vulnerable to more frequent wake ups, as well as cognitive decline (*Summer & Rehman, 2023*).

Types of sleep disturbances

COMMON SLEEP ISSUES IN PD INCLUDE:

- 1. Insomnia:** This sleep condition makes falling, staying, or going back to sleep hard. It is one of the most common sleep problems, with 30% of all adults reporting some degree of it; however, people with PD are even more likely to experience insomnia (*Parkinson's Foundation, n.d.*).
- 2. Excessive daytime sleepiness (EDS):** As its name suggests, EDS can result in undesirable sleepiness during hours you may prefer to be awake. It affects around half of people with PD with considerable impacts on quality of life. EDS can be triggered by a class of medications commonly used to treat PD called dopamine agonists, though it can also occur with levodopa (*Knie et al., 2011*).
- 3. REM sleep behaviour disorder (RBD):** This sleep disorder is common in people with Parkinson's. Those with RBD lack the normal muscle paralysis that prevents most people from acting out their dreams during REM sleep. While this paralysis sounds scary, it actually keeps us safe. Without it, people with RBD may kick, shout, or punch during sleep. In severe cases, they may need to sleep alone to avoid harming their bed partner (*Mahmood et al., 2020*).

4. **Sleep apnea:** Sleep apnea is characterized by irregular breathing patterns during sleep, such as pauses in breathing or shallow breaths. It may be caused by the disease's impact on the upper airway (*Maggi et al., 2023*).
 5. **Sleep fragmentation:** This occurs when sleep is frequently broken up, resulting in an individual being unable to get enough deep, restorative sleep. Research comparing sleep stages between people with PD and age-matched controls shows that those with the disease spend significantly less time in both slow-wave (the deepest stage of sleep) and REM sleep, as mentioned above. The impact can be serious, as fragmented sleep is associated with medication-induced hallucinations and increased daytime sleepiness (*American Parkinson Disease Association, n.d.*).
 6. **Frequent urination at night (nocturia):** Nocturia is one of the most common non-motor symptoms amongst people with PD, with over 50% of those with the disease needing to urinate at least twice per night (*Batla et al., 2016*).
- **Stick to a routine – even on weekends:** Maintaining a consistent routine might be one of the most important ways to get a restorative night's sleep because it helps tune our body's internal clock. In fact, one study found that a routine could lower your chances of dying from all causes by 30%, and that sleep regularity is even more important than sleep duration (*Zuraikat et al., 2023*)!
 - **Tap into the power of exercise:** You may have already heard that exercise can boost sleep quality, as well as making it easier to fall asleep. However, a 2022 study was the first to find that high-intensity exercise, including resistance and body-weight interval training, could improve sleep spindle density in people with Parkinson's, which was associated with improved memory. These findings suggest that exercise may have potential benefits for both sleep quality and cognitive function in PD (*Memon et al., 2022*). No matter how you choose to move, just get moving (your body and mind will thank you!), though it is best to avoid strenuous exercise right before bed, as it can raise your core temperature and make it hard to fall asleep.
 - **Take charge of your mental health:** Many individuals with PD experience mental health challenges, such as depression and anxiety, which can interfere with sleep quality and quantity. These conditions are treatable, so make sure to speak with your doctor, or get in touch with Parkinson Society BC's counsellors for confidential, free counselling. Learn more at www.parkinson.bc.ca/counselling

Strategies for improving sleep

- **Optimize your medication:** With guidance from your neurologist or doctor, switching to a longer-lasting or extended-release form of medication may help manage your symptoms throughout the night. Some individuals may need to switch to a different class of medications altogether; for example, people with excessive daytime sleepiness caused by dopamine agonist use may need to try other drugs with less risk of EDS, such as MAO-B inhibitors (*Di Laudo et al., 2023*). Always speak with your doctor to get the best advice for your situation.
- **Avoid blue light in the evening:** Experts have been warning about the impact electronics are having on our sleep for a good reason – the blue light emanating from our screens has a profound effect on our 24-hour cycle, also called the circadian rhythm. The content we consume electronically can also be very stimulating, revving up our minds right when they need to get ready for bed. Opt instead for a relaxing, old-fashioned book before sleep (*Newsom & Singh, 2024*).

Sleep disturbances are a common and challenging issue for people with Parkinson's disease, significantly impacting their overall wellbeing. The complex interaction between the disease itself and the medications used to treat it can worsen problems like insomnia, excessive daytime sleepiness, and fragmented sleep. However, there are practical steps that can help. By understanding these challenges and applying targeted strategies, individuals with Parkinson's can work towards better sleep and an overall improved quality of life.



SOURCES

- American Parkinson Disease Association (n.d.). Sleep Problems. <https://www.apdaparkinson.org/what-is-parkinsons/symptoms/sleep-problems/>
- Batla, A., Phé, V., De Min, L., & Panicker, J. N. (2016). Nocturia in Parkinson's Disease: Why Does It Occur and How to Manage? *Mov Disord Clin Pract*, 3(5), 443–451. <https://doi.org/10.1002/mdc3.12374>
- Chahine, L. M., Daley, J., Horn, S., Duda, J. E., Colcher, A., Hurtig, H., Cantor, C., & Dahodwala, N. (2013). Association between dopaminergic medications and nocturnal sleep in early-stage Parkinson's disease. *Parkinsonism & Related Disorders*, 19(10), 859-863. <https://doi.org/10.1016/j.parkreldis.2013.05.009>
- Di Laudo, F., Baldelli, L., Mainieri, G., Loddo, G., Montini, A., Pazzaglia, C., Sala, M., Mignani, F., & Provini, F. (2023). Daytime sleepiness in Parkinson's disease: A multifaceted symptom. *Frontiers in Sleep*, 2, Article 1302021. <https://doi.org/10.3389/frsle.2023.1302021>
- Knie, B., Mitra, M. T., Logishetty, K., & Chaudhuri, K. R. (2011). Excessive daytime sleepiness in patients with Parkinson's disease. *CNS Drugs*, 25(3), 203–212. <https://doi.org/10.2165/11539720-000000000-00000>
- Levine, H. (2024). REM sleep: What is it, why is it important, and how can you get more of it? <https://www.health.harvard.edu/staying-healthy/rem-sleep-what-is-it-why-is-it-important-and-how-can-you-get-more-of-it>
- Mahmood, Z., Van Patten, R., Nakhla, M. Z., Twamley, E. W., Filoteo, J. V., & Schiehser, D. M. (2020). REM sleep behavior disorder in Parkinson's disease: Effects on cognitive, psychiatric, and functional outcomes. *Journal of the International Neuropsychological Society*, 26(9), 894–905. <https://doi.org/10.1017/S1355617720000430>
- Memon, A. A., Catiul, C., Irwin, Z., Pilkington, J., Memon, R. A., Joop, A., Wood, K. H., Cutter, G., Bamman, M., Miocinovic, S., & Amara, A. W. (2022). Effects of exercise on sleep spindles in Parkinson's disease. *Frontiers in Rehabilitation Sciences*, 3, Article 952289. <https://doi.org/10.3389/frsc.2022.952289>
- Newsom, R. & Singh, A. (2024). *Blue Light: What It Is and How It Affects Sleep*. <https://www.sleepfoundation.org/bedroom-environment/blue-light>
- Parkinson's Foundation (n.d.). *Sleep Disorders*. <https://www.parkinson.org/understanding-parkinsons/non-movement-symptoms/sleep-disorders>
- Stefani, A., & Högl, B. (2020). Sleep in Parkinson's disease. *Neuropsychopharmacology Reviews*, 45, 121–128. <https://doi.org/10.1038/s41386-019-0448-y>
- Summer, J. & Rehman, A. (2023). *Sleep Spindles*. <https://www.sleepfoundation.org/how-sleep-works/sleep-spindles>
- Zuraikat, F. M., Aggarwal, B., Jelic, S., & St-Onge, M.-P. (2024). Consistency is key: Sleep regularity predicts all-cause mortality. *Sleep*, 47(1), zsad285. <https://doi.org/10.1093/sleep/zsad285>

Stories

A culture of caring: How A&W is making a profound difference for people with Parkinson's

Holly and Chris Parrish's longstanding involvement with Parkinson Society British Columbia (PSBC) is deeply rooted in their desire to make a positive impact on their community. For over two decades, the fundraising efforts of their A&W franchise locations in Newton, Strawberry Hill, and Cloverdale in Surrey, as well as Glenlyon in Burnaby have raised an astounding \$235,000 for the Society. This achievement is a testament to the values they hold, as well as their ability to inspire others to contribute to this important cause.

A proud breast cancer survivor since 2010, Holly's journey taught her that the most important things in life are the people who surround you. She embraces hope, gratitude, and positivity in all challenges. While she says her work is a full-time job and more, Holly remains a passionate traveler. Within A&W, Holly is a dedicated coach who strives to lead with compassion and her legacy in mind, inspired by her father's example.

Chris grew up in a sports-oriented family, which helped shape his core values and guide his personal and professional life. Starting out as an A&W cook, Chris now leads his family's business.

The couple's personal journey with Parkinson's disease (PD) began when they noticed Chris' mother, Carole, had a small tremor in her hand. At first, they were unsure whether to ask about the symptom or worry, but as Carole's shaking became more noticeable, she was ultimately diagnosed with Parkinson's in 1997. Holly and Chris' lives were very busy then, juggling their roles as new A&W franchisees while also parenting two small children.

Chris recalls that despite the challenges, the diagnosis made their family more mindful of living in the present moment. "These things help shape your decisions on what is important in life. Mom's



Chris at the Nat

diagnosis made my parents make decisions that pushed forward focusing more on today and not so much tomorrow – because we have to remember tomorrow is never guaranteed, or at least not in the way we think it will look like," he says.

A year after Carole's diagnosis, Holly and Chris built their third A&W location, which would become the starting point of combining their business, classic car shows, and fundraising for PSBC. Their fundraising journey began in 2000, with a car show in the parking lot of their newly-built Surrey location. It was perfect timing because A&W was heavily involved in the 'Cruisin the Dub' event, and the classic car scene was booming. "It also helped that we had a few classic car enthusiasts in my dad, uncles, and their car clubs," says Holly.

Starting with as many cars as they could fit into the lot, they invited families and the community at large to come and join them. The event featured bouncy castles, face painting, a silent auction generously supported by local businesses, and the fan favourite: a root beer chugging contest.

As the Car Show for Parkinson's grew, they relocated to their Newton A&W, eventually welcoming over 150 classic cars. The couple even traveled to other car shows to promote their event, building relationships with clubs throughout the Lower Mainland. While weather was always a gamble, Holly remembers fondly how rain or shine, people still came. "The Cruisers became our family and friends," she reflects. "We were absolutely blessed and thankful to our team, friends, family, local businesses, community, and others for their unlimited support to our cause."

When A&W partnered with the Vancouver Canadians baseball team, Holly and Chris saw another fundraising opportunity. At the Canadians' games, head office would donate supplies for 1,000 root beer floats and the teams ran root beer float stands, with 100% of donations going to PSBC. "We were usually sold out by the third inning," Holly says proudly. The team then got to do a cheque presentation with the A&W Root Bear on the field. The highlight of this partnership for Holly and Chris was the first year when their son, Coleton, got to throw the first pitch of the game alongside the A&W Root Bear.

Involving their A&W teams in these initiatives has not only been vital for fundraising, but it has also become central to the culture of their restaurants. "We are truly in the people business versus the restaurant business. We do everything through our teams, and we have to work together for all that we do," Holly emphasizes. "'Together' is a strong, impactful word and feeling that drives our culture – belief that we are all in this together."

Every April, the teams excitedly gear up for Parkinson's Tulip Card Sales, with each store setting a fundraising goal. Friendly competition between locations and the incentive of exciting prizes spurs even more enthusiasm. Each store is given a goal to achieve, and teams work together for success. The stores also get creative with the theme, creating bright and beautiful tulip arrangements. Beyond the support of their staff, Holly and Chris are grateful for their valued guests. "They are the real heroes that say 'yes' to rounding up their receipts, donating a dollar or toonie, or even more," Holly says.

Holly recounts one particularly touching moment involving her mother, who is also a regular at their A&W locations. One day, a new staff member, unaware of who she was, asked if she would like to donate to Parkinson Society BC. When her mother said she'd donate \$20, the employee was stunned and shared the story with the rest of the team. "I visited the location on the same day, and the buzz about the lady who donated \$20 was still circulating," Holly says. "I could not do anything but smile and celebrate their accomplishment, knowing already that it was my mom."



A&W Root Bear's first pitch at the Nat



The family has also been active supporters of Parkinson SuperWalk, the Society's flagship fundraising event. Each year, after their stores have completed six weeks of fundraising, Chris and Holly launch their own campaign, raising additional funds to reach a yearly goal of \$10,000 with the help of friends, family, and business associates.

Holly recalls that no matter the weather, their loved ones always showed up to support them at SuperWalk. Participating in the walk has left Holly and Chris with endless fond memories, including one featuring the A&W Root Bear leading the warmup exercises before the walk. "It was priceless to see him doing his stretches or bopping to the music," says Holly. Chris adds that being a part of SuperWalk has helped teach their children compassion and empathy.

The COVID-19 pandemic did not stop them from keeping the Parkinson SuperWalk spirit alive either. Holly created a virtual walk in Cultus Lake, where Carole now lives, putting up motivational signs and balloons along the route. They decorated Carole's electric scooter and carried a SuperWalk flag on a broom stick. This got the attention of neighbours, who first came to see what the event was and then became cheerleaders for the group. "SuperWalk was so important to my mother-in-law, and I am glad we could bring the walk to her," Holly says.

As Parkinson's disease progressed for Chris' mother, the family turned to Parkinson Society BC for support. Holly has attended the Advanced Parkinson's Support Group, gaining insights from other caregivers and PSBC's resources. When her mother-in-law became seriously ill and was hospitalized, Parkinson Society BC's Aware in Care Kit played a crucial role in further educating her healthcare team about Parkinson's and advocating for medication on time, every time, which is essential for people with PD. After Carole came home from the hospital, PSBC was there to help ease this transition, helping the family adapt to round-the-clock care. Holly also adds that the emotional support the Society was able to provide during this trying time was invaluable.

For those with loved ones living with Parkinson's, Holly offers this advice: "Don't be shy or too proud to ask for help. Use the resources available – you don't have to do it alone!" She stresses the importance of patience, both with loved ones and with oneself, and reminds caregivers to take time for self-care.



Carole at Parkinson SuperWalk



A&W team

Holly and her family are deeply grateful for the unwavering commitment the Society demonstrates, not only in advancing research but in providing vital support for those living with Parkinson's disease in this province. She emphasizes that the individuals on the Parkinson Society BC staff are dedicated and passionate. "The team members may have changed over the years, but they never falter in the goal they are trying to achieve," she says.

Holly and Chris' dedication to Parkinson Society BC is a reflection of their commitment to making a meaningful difference. Through their fundraising efforts and community involvement, they have created a legacy of support and care. Their story is a powerful reminder that, together, we can build a stronger, more compassionate community – one where nobody faces Parkinson's alone.



A&W team hard at work



Chris and Carole

Parkinson Society BC would like to thank Holly and Chris Parrish, as well as the entire A&W team, for their generous support. Donations from individuals and businesses are critical to help empower the PD community in British Columbia. If you would like to make a difference, please consider organizing a third-party event or making a donation at www.parkinson.bc.ca/donate.



Carole with cheque presentation



PARKINSON SUPERWALK®

Total Raised by Our Community¹

\$354,455.26... and counting!

Everyone's incredible support of Parkinson SuperWalk in 2024 has helped raise \$354,455.26... and counting!

These funds directly support Parkinson Society BC's mission to empower people with Parkinson's by providing resources and services to enable self-management, self-reliance, and self-advocacy. Thank you to everyone who participated, donated, and volunteered, and we can't wait to see you again next year!

For the most up-to-date SuperWalk totals and photos, visit www.parkinson.bc.ca/superwalk

100 Mile House	\$5,158.70
Abbotsford	\$7,261.25
Burnaby (Virtual)	\$556.00
Chilliwack	\$9,880.70
Comox Valley	\$6,705.05
Kamloops	\$40,272.00
Kelowna	\$70,727.35
Langley (Virtual)	\$863.50
Nanaimo (Virtual)	\$50.00
New Westminster	\$7,324.50
Parksville/Qualicum Beach	\$20,071.60
Pitt Meadows/Maple Ridge	\$12,267.00
Prince George	\$8,292.75
Richmond (Virtual)	\$280.00
Salmo	\$8,947.40
Vancouver	\$100,825.09
Vernon	\$11,451.80
Victoria (Virtual)	\$2,376.85
Virtual Walkers	\$13,979.92
White Rock/Surrey	\$27,163.80

Thank You to Our Provincial Sponsors



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¹ We endeavour to provide accurate listings using the information available at the time of publishing. If there is information you are aware of that has been overlooked, please contact us.



Top Fundraising Individuals

SUPERB SUPERSTAR WALKERS (RAISED \$5,000+)

Chilliwack: Angela Hutchinson

Kamloops: Rendy Olthuis, Jane Osterloh

Kelowna: Deborah Hartley, Garry Toop

Vancouver: Holly Parrish, **TOP FUNDRAISER Deborah Yeates**

Virtual Walker: Wendy Murray

White Rock/Surrey: Cinesio Rocha

SUPERSTAR SUPREME WALKERS (RAISED \$2,500-\$4,999)

100 Mile House: Philip Konrad

Abbotsford: Carolyn Krahn

Comox Valley: Paul Atterton

Kamloops: Daryle Arden, Janice Hobbs, Rodney Hobbs

Kelowna: Adam Rich, Carole Taylor, Jenny Wright

New Westminster: Kathy Lynn

Salmo: Gordon Wallace

Vancouver: Elspeth Banerd, Tracey-Lee Eddy, Margaret Mutch, Patricia Rupper, Valerie Zilinski

Vernon: Wray McDonnell

White Rock/Surrey: Emily Chadwick

SUPERSTAR WALKERS (RAISED \$1,000-\$2,499)

Abbotsford: Anita Hildebrandt, James Matthies

Chilliwack: Clifford Roulston

Kamloops: David Farrow, Barbara Johnson, Alf Konrad, Ian McKichan, Rita Schneider, Susanne Touhey

Kelowna: Jean Flintoft, Don Kerr, Carol Millar, Mitchell Peterson, Ashley Richardson

New Westminster: Joseph Resendes, Ronald Thomas

Parksville/Qualicum Beach: Mark Beuerman, William Chipman, David Field, Doug Pickard, Tim Struch, Tiffany Taylor

Pitt Meadows/Maple Ridge: Paula Clarke, Edith Elliott, Wim Hunfeld, Richard Maki

Vancouver: Wayne Babcock, Jan Carley, Teagan Cartwright, Annie Kuan, Jennifer Lorz, Robert Mackin, Richard Mayede, Olivia Moore, Chris Parrish, Barbara Robertson, Margot Schultz, Athalie Scott, Martti Solin, Bonnie Sun, Joe Vampa, Eric Van den Kerkof, Courtney Vasquez

Vernon: Leslie Davidson, Dwight More, Joseph Nagraeff

Victoria (Virtual Walk): James Park

Virtual Walkers: Sylvia Bull, Bente Svendsen

White Rock/Surrey: Don Bedwell, Shelley Jackson

Top Teams

BC TEAMS (RAISED \$1,000+)

Abbotsford: ParKrahn

Comox Valley: In Memory of Bev White

Kamloops: Arden Team, Berwick Kamloops, Rita's Movers and Shakers, Shake, Rattle & Roll (Kamloops), Team Colleen, Touhey's Travelers

Kelowna: **TOP TEAM Good Vibrations**, Lloyd Peterson, OK Movers, Ted E Bears

New Westminster: Century House Parkinson's Group, Manuel F Resendes

Parksville/Qualicum Beach: chipfam, Gram's Gang, PD Warriors, Parksville Superwalkers, Walking the Fields for Bill

Pitt Meadows/Maple Ridge: Lumbering Lloyds, Pop's Posse, Team Wendy

Salmo: Salmo Shakyvanguy Team

Vancouver: A&W Cruisers, Bowenators for Parkinson's, Mayede, Pacific Parkinson's Research Centre, Red Hot Chilli Steppers, Remembering Bryan, Solin Perhe, Tapestry Arbutus Walk, Team Gran, Team Wayne, Tedster 2.0, Walk for moms, Walking for Concetta

Vernon: Helping for the Future, Team McDonnell, The Bumbling On's

Victoria (Virtual): Team Caniwi

White Rock/Surrey: Buena Vista Massage, Shake it off, Team Bee, Walking for Rand Walker



2025 At a Glance

Parkinson Society British Columbia (PSBC) is pleased to announce our tentative education and support services plan for the upcoming year. More details will be provided on our website as they become available. *Schedule is subject to change.*

Upcoming Events

ONLINE WORKSHOPS AND IN-PERSON CONFERENCES

January (Virtual): **Nutrition and PD**

February (Virtual): **Intimacy and PD**

February (Virtual): **New Diagnosis Series**

Williams Lake (April), Cranbrook (May), and Surrey (October) (In-Person):

Communication and Swallowing Workshops

March (Virtual): **Wellness**

September (Virtual): **Global Symposium Series**

November (Virtual): **Caregivers' Series**

Spring and Fall (In-Person): **Regional Conferences**

(In-Person): **Community Talks**

ONLINE EXERCISE CLASSES

Balance Exercise Series: Thursdays, January 2 – 30

Boxing: Tuesdays, February 4 – 25

April Challenger: Thursdays, April 3 – 24

Chair Yoga: Mondays, May 5 – June 2; October 6 – 27

September Challenger: Thursdays, September 4 – 25

Zumba: TBD

Tai Chi/Qi Gong: TBD

Let's Get Loud Voice Classes: TBD

ACTIVITIES

Coffee Connect: Every Wednesday

SongShine: TBD

Mime over Mind: TBD

- Mime may help retrain the brain by using fine and large motor skills, imagery, and motor memory. Participants will learn three mime concepts, helping make an invisible object appear solid to the audience.

Improv: TBD

- Improv (improvisational theater) for wellness can have a profound effect on individuals with Parkinson's and may lead to improved physical coordination, increased self-esteem, and a sense of belonging.

Cognitive Behavioural Therapy (CBT) Sessions: TBD

Information and Referrals: Ongoing service is available by telephone or email. If we are unable to answer your questions or concerns immediately, we will research your inquiry and get back to you.

Counselling & Healthcare Navigation (CHCN):

Parkinson Society BC acknowledges the multifaceted challenges of living with Parkinson's. Our Counselling & Health Navigation team, made up of a clinical counsellor and social worker, offers free services through three focused pathways:

1. **Short-term psychotherapy:** Tailored therapy addressing emotional complexities such as anxiety, depression, and grief, fostering resilience, and emotional well-being.
2. **Psychoeducation:** Equipping individuals with knowledge on disease progression, treatment, and effective coping strategies for managing daily life.
3. **Healthcare navigation:** Simplifying the complex healthcare system through advocacy, explanation of medical information, community resource connections, long-term care planning guidance, and disability benefits assistance.

Support Groups: Throughout the year, we will continue to provide optimal support to our support groups with regular contact via check-ins by phone, virtual one-on-one and group touchbase meetings with facilitators, as well as in-person visits when possible. To ensure ongoing support, we will maintain the GroupLink monthly publication, schedule facilitator webinars as needed and offer PSBC's annual facilitator training workshop. We will also continue to foster our support group needs and participation. We welcome all invitations to visit, however, please connect with PSBC for updated details of each support group.

Virtual Physiotherapy: We believe every person with Parkinson's disease should have access to a physiotherapist who is experienced in treating movement disorders and neurodegenerative diseases. However, geographic and/or financial barriers may make this inaccessible for many individuals. To increase access to Parkinson's-specific therapies, we launched a virtual physiotherapy service in 2021. Our own neuro physiotherapist provides phone or video-conferencing sessions free of charge for people meeting certain criteria.

PD Connect®: We will continue to increase awareness of PD Connect®, a referral program intended to help healthcare professionals connect individuals diagnosed with Parkinson's disease and their carepartners to PSBC's support services at the time of diagnosis or at any point in the disease progression.

PDLink: We will continue with this peer program that connects persons living with Parkinson's and carepartners on a one-to-one basis for support. Individuals will be connected based on similar experiences. Connections are maintained through phone, Zoom, and email only.

Healthcare Professional Bursary Program:

- Continuing Education Bursaries (6 x \$1,000.00)
- PD Warrior Level 1 + 2 training in late summer/fall (location TBD)

Online Resources: We will continue to produce up-to-date resources for people affected by Parkinson's, as well as healthcare professionals. In addition to making recordings of presentations available on our website and YouTube channel, we will distribute them through our publications, like Good News, GroupLink, and Pathways.

Newsworthy

Upcoming Education & Exercise Events



Thursday, December 12 from 1:00 – 2:00pm

Holiday Caroling

🌐 Online

Jingle all the way with Joani Bye in this festive caroling event! Sing along to holiday classics and enjoy the joy of music as we celebrate the holiday season together while relaxing and practicing your linguistic and vocal skills.

**Thursdays, January 2, 9, 16, 23, & 30
from 10:00 – 11:00am**

Balance Exercise Series – Level 1

🌐 Online

Kickstart your new year with a five-week series of low-impact balance exercises. Led by PSBC's neuro physiotherapist, Shelly Yu, the class will focus on agility-type activities to improve everyday balance, such as multidirectional stepping, weight shifting, and turning.

**Tuesdays, February 4, 11, 18, & 25
from 12:25 – 1:25pm**

Rock Steady Boxing with Doug – Level 2

🌐 Online

Are you ready... to Rock Steady? Join us for an eight-week fitness boxing class for Parkinson's. This class is a total workout for both mind and body as it incorporates cardio, strength, balance, hand-eye coordination, and speed!

Stay Connected to the Parkinson's Community

It's that time of year again! Renew your membership with Parkinson Society British Columbia and continue to be part of our friendly, caring, and supportive community.

For only \$25, you will receive an annual membership for you and your household, valid until December 31, 2025. *Reasons to renew your membership:*

Get Discounts

Your membership provides you with great discounts on events that are not to be missed!

Be Heard

Vote at our Annual General Meeting and add your voice to the community to garner support from donors, sponsors, and politicians.

Stay Informed

Get the latest information on research, medication, caregiving, exercise, wellbeing, and nutrition when you receive our quarterly magazine, Viewpoints, and other publications.

Gain Support

Link to our provincial network of over 50 support groups, and speak with our knowledgeable and compassionate staff.

www.parkinson.bc.ca/membership



Questions? Contact Susan Atkinson at 1-800-668-3330 ext 263 or satkinson@parkinson.bc.ca



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