

UPCOMING EVENTS

- Popping for Parkinson's | Mondays, September 4, 11, & 18
 - Learn more & register: https://bit.ly/popforPD-23
- Move with Confidence: Parkinson's Fitness | Tuesdays, September 5, 12, 19 & 26
 - Learn more & register: https://www.parkinson.bc.ca/movewconf-augsept23
- SongShine with Joani | Thursdays, September 7 & 14
 - Learn more & register: https://www.parkinson.bc.ca/songshine-augsept23
- Thawing Out: Exercises for Freezing | Thursdays, September 7, 14, 21 & 28
 - Learn more & register: https://www.parkinson.bc.ca/freezing-sept23
- Navigating Employment with Young Onset Parkinson's | Wednesday, September 13
 - Learn more & register: https://www.parkinson.bc.ca/employmentyopd-sept23
- Communication and Swallow Workshop | Saturday, September 16
 - Learn more & register: https://www.parkinson.bc.ca/csw-victoria23
- Painting and Play: Expressive Arts Therapy (A) | Wednesdays, September 20, 27, and
 - October 4, 11, 18 & 25
 - Learn more & register: https://www.parkinson.bc.ca/arttherapy-a
- SongShine with Joani | Thursdays, September 21, 28, and October 5, 12, 19 & 26
 - Learn more & register: https://www.parkinson.bc.ca/songshine-septoct23
- Painting and Play: Expressive Arts Therapy (B) | Fridays, September 22, 29, and October
 6, 13, 20 & 27
 - Learn more & register: https://www.parkinson.bc.ca/arttherapy-b
- Mood and Motivation | Tuesday, September 26
 - Learn more & register: https://www.parkinson.bc.ca//moodmotiv-sept23
- Rock Steady Boxing | Tuesdays, October 3, 10, 17, 24, 31 and November 7, 14, 21 & 28
 - Learn more & register: https://www.parkinson.bc.ca/rsb-octnov23
- Psychiatric Issues | Wednesday, October 18
 - Learn more & register: https://www.parkinson.bc.ca/psychissues-oct23
- Unlocking Insights: Imaging and Biomarkers in Parkinson's | Monday, November 13
 - Learn more & register: https://www.parkinson.bc.ca/imagingbiomarkers-23



Parkinson SuperWalk

Beginning the weekend of September 9 and 10, incredible British Columbians in more than 20 communities throughout the province will walk together to help give hope to approximately 15,000 people in BC living with Parkinson's disease. We invite you to join us for SuperWalk, our largest fundraiser of the year, in a community near you. [learn more and register]

Donate a Car Canada

<u>Donate a Car Canada</u> accepts Vehicle Donations for Parkinson Society British Columbia (PSBC)! Free towing is provided in most areas across Canada. When you donate your car, truck, RV, boat, or motorcycle to PSBC through Donate A Car Canada, it will either be recycled or sold at auction (depending on its condition, age, and location). After your vehicle donation is complete, PSBC will send you a tax receipt and will put your gift to good use.

Brighten the day with a bouquet from Callia Flowers

For a limited time, <u>Callia Flowers</u> is offering Parkinson Society BC's (PSBC) community members a \$5 discount on any order they place using the code: **PARKINSONBC**. With every order placed using the custom code, Callia will donate 10% of the net sales to the Society. Join us in making a meaningful impact in our community and spread the love with Callia Flowers today!

We are looking for more Champions!

Do you want to help fund research, grow support networks, and improve quality of life for those living with Parkinson's disease (PD)? Become a Champion for Parkinson's and plan your own independent community fundraising event! Contact us at events@parkinson.bc.ca or 1-800-668-3330.

TIP JAR

The Tip Jar is where we share advice from Parkinson's community members on a wide range of topics from daily lifestyle hacks to safety. This month we share a tip on taking medication!



Bring along portable apple sauce packets when you're on the go, travelling or engaging in physical activities. These can be a convenient way to accompany your medication, helping to manage any potential issues with timing.

Do you have any tips or tricks that you would like to share with the Parkinson's community? These can be tips from something that works well, to eating and dressing, to getting out of bed or travelling! All tips and tricks are welcome! Please share your ideas at info@parkinson.bc.ca.

NEWS & ANNOUNCEMENTS

Seeking Support Group Facilitators

Parkinson Society British Columbia is currently seeking volunteer support group facilitators for Abbotsford (online and in-person), Richmond (online), Campbell River, Tri Cities, and West Vancouver (online). [learn more]

Shape Tomorrow's Care Today

Consider including Parkinson Society BC in your estate planning. Your thoughtful gift can support vital programs and services. Whether through RSPs, TFSAs, or other means, your gift symbolizes a continued commitment to those living with Parkinson's disease, their caregivers, and families. [learn more]

Join PSBC's Book Club!

PSBC's Book Club is a social club for like-minded people who have PD, or carepartners of those with PD, to meet and discuss books that are selected by the peer committee or group members. The group meets at 11:30 am on the first Thursday of each month. If you are interested in joining this virtual, peer-led book club, please contact Alana Dhillon.

DISCUSSION TOPIC: Non-Motor Symptoms

Discussion Questions



- 1. Have you noticed any non-motor symptoms alongside the more commonly known motor symptoms of Parkinson's disease? How have these non-motor symptoms affected your daily life and overall well-being?
- 2. How do non-motor symptoms intertwine with your motor symptoms of Parkinson's?
- 3. Have you discussed these symptoms with your healthcare provider? If not, what might be some barriers to initiating this conversation?
- 4. What coping strategies or interventions have proven effective in addressing specific non-motor symptoms, such as anxiety, depression, sleep disturbances, or cognitive challenges? Are there any unique approaches that you've found particularly helpful?

Parkinson's disease (PD) is commonly associated with motor symptoms such as tremors, bradykinesia (slow movement), and stiffness. However, it's important to recognize that non-motor symptoms (NMS) also play a significant role in the disease. Certain symptoms, including anosmia (loss of smell), constipation, depression, and rapid eye movement sleep behavior disorder (RBD), may even manifest many years prior to the official diagnosis of Parkinson's disease (Hermanowicz et al., 2019). Most non-motor symptoms can fall into one of three major categories: autonomic dysfunction, cognitive and psychiatric symptoms, and sleep disorders.

Research findings indicate that among individuals with PD, the most reported non-motor symptoms fall within the miscellaneous domain, encompassing issues like pain, altered sense of smell, excessive sweating, and weight changes. Sleep-related symptoms, urinary symptoms, gastrointestinal symptoms, and mood/cognition disorders are also prevalent. While attention deficit, cardiovascular symptoms, and sexual dysfunction are less frequent, they remain common. On the other hand, symptoms linked to hallucinations and perception are found to be the least frequently reported among non-motor symptoms (Berganzo et al., 2016).

NMS can be just as if not more disabling as motor symptoms, affecting the individual's quality of life and impacting relationships. Due to their less visible nature, these symptoms are often underestimated, leading to inadequate recognition and treatment. As such, it's crucial that



healthcare providers and caregivers are aware of the full range of symptoms that PD can cause and work to manage each of them effectively.

Screening for Non-Motor Symptoms

Screening for non-motor symptoms in Parkinson's disease (PD) is a vital component of comprehensive patient care. One effective method to screen for non-motor manifestations in Parkinson's is a specialized tool known as the Non-Motor Symptoms Questionnaire (NMS-Quest). It is a clinical instrument consisting of 30 yes-no questions, each targeting a distinct non-motor symptom which can occur in all stages of Parkinson's disease (Zis et al., 2015). Administering the NMS-Quest during or prior a clinic visit allows individuals with PD to provide valuable insights into their non-motor symptomatology. You can even access the questionnaire yourself (linked above) before an appointment with someone from your healthcare team. Subsequently, the clinician can assign a numerical grade to quantify the burden of non-motor symptoms. Patients are typically requested to highlight the symptoms causing the greatest discomfort. This information can then be utilized by healthcare professionals to initiate informed discussions, tailor treatment plans, and address the holistic well-being of patients (Todorova et al., 2014). The identified symptoms can then be targeted via approaches such as pharmacological interventions, specialized therapies offered by health experts, or input from neuropsychological and neuropsychiatric professionals. This tool allows the individual's healthcare team to assess the burden of additional symptoms and their impact on quality of life. It is recommended to regularly document non-motor symptoms to track the trajectory over time.

Impact of Non-Motor Symptoms

Non-motor symptoms encompass a diverse range of challenges that span over cognitive, emotional, autonomic, and sensory domains. Research shows that these symptoms are pervasive, affecting up to 90% of individuals with PD, often preceding the onset of motor symptoms (Hermanowicz et al., 2019). The severity of these symptoms is closely linked to the loss of self-sufficiency, the need for residential placement among individuals with PD, and the



extent of caregiver burden. Therefore, they are found to have a greater influence on the overall quality of life for individuals with PD and their caregivers compared to motor symptoms (Bock et al., 2022).

In a research study that examined individuals with Parkinson's disease (PwP) and their caregivers, over half of the participants reported that non-motor symptoms (NMS) had either a moderate or significant adverse effect on various aspects of daily life. These impacts were observed in activities such as running errands (53%), household chores (53%), self-care routines (72%), arranging social activities with friends and family (57%), engaging in social interactions with friends and family (58%), dining out (69%), and attending movies (61%) (Hermanowicz et al., 2019). Specific cognitive changes, such as memory difficulties, attention impairments, and deficits in executive function, can hinder decision-making and reduce independence, thereby further complicating these daily tasks. The study showcases the breadth of activities, including essential tasks impacted, which play a crucial role in maintaining personal independence and quality of life. Additionally, the study shows that NMS hinder the ability to engage in social activities, both in terms of arranging events with friends and family and participating in interactions. These activities are essential in building and maintaining interpersonal relationships which hold significant value to general happiness levels. (Ross & Mirowsky, 2002)

In the same study, 50% of participants expressed that their friends and family had limited comprehension or lacked understanding regarding how Parkinson's disease affects their daily life (Hermanowicz et al., 2019). This underscores the need for a comprehensive understanding of Parkinson's disease that encompasses both its motor and non-motor aspects. The findings also emphasize the importance of support networks, such as caregivers and support groups, in comprehending the multifaceted challenges faced by people with Parkinson's (PwP). Detecting and addressing NMS at an early stage may allow for more comprehensive and personalized interventions, ultimately improving quality of life. It can also enhance the well-being of caregivers and extend the duration that PwP actively participate within their community (Hermanowicz et al., 2019).



The Interplay Between Motor and Non-Motor Symptoms

Motor and non-motor symptoms in PD are not isolated occurrences but are deeply interconnected, often influencing and exacerbating each other. For instance, anxiety, depression, and sleep disturbances can intensify motor symptoms and conversely, motor fluctuations can worsen cognitive function. This intricate interplay has far-reaching consequences, often resulting in a cycle of mutual influence where the progression or alleviation of one type of symptom affects the trajectory of the other. Non-motor fluctuations often arise simultaneously with motor fluctuations, contributing to the complex connection between the symptoms. Certain non-motor symptoms are exacerbated during 'off' periods, which are times when PwP experience reduced medication effectiveness, while others exclusively manifest during these 'off' periods (Todorova et al., 2014).

Non-motor symptoms that worsen during 'off' periods

- Fatigue
- Depression
- Anxiety
- Inner Restlessness
- Impaired Concentration/Attention

Non-motor symptoms occurring only/exclusively during 'off' periods

- Fatigue
- Depression
- Anxiety
- Impaired concentration
- Inner restlessness
- Pain
- Excessive Sweating

Addressing non-motor symptoms may not only enhance the patient's overall quality of life but also indirectly impact the severity and progression of motor symptoms. Understanding this interaction also sheds light on the potential use of non-motor symptoms as early markers for



disease progression. This interplay underscores the need for holistic care approaches that address the interconnectedness of these symptoms and enhance overall well-being.

Strategies for Managing Non-Motor Symptoms

The management of non-motor symptoms in PD presents an urgent and often unmet need. These symptoms frequently escape the attention of clinicians, leading to the oversight of important issues like depression, anxiety, fatigue, and sleep disturbances. Left unaddressed, these non-motor symptoms can significantly deteriorate quality of life, often leading to hospitalization, which in turn results in a fourfold increase in the overall cost of care (Todorova et al., 2014). The complexity of the interplay between non-motor and motor symptoms poses challenges in effectively targeting and treating these symptoms. To tackle non-motor symptoms effectively in Parkinson's, a multidisciplinary approach is essential, incorporating medical, psychological, and lifestyle interventions (Fereshtehnejad et al., 2021). Customized treatment plans must consider the individual's specific symptom profile and overall health. PwP can optimize overall care through the collaboration across healthcare professionals such as physical/occupational therapists, speech language pathologists, and dieticians. Among the effective treatments, cognitive rehabilitation, behavioral therapies, and pharmacological interventions are vital for addressing cognitive changes and mood disorders. Furthermore, combining sleep hygiene practices with suitable medications can help alleviate sleep disturbances. Numerous studies attest to the positive impact of regular physical activity on both motor and non-motor symptoms, while dietary adjustments may effectively manage gastrointestinal issues. Engaging in targeted activities like music and dance-based interventions has also been shown to effectively enhance emotional and social well-being (Subramanian et al., 2023).

Additionally, fostering a supportive environment through support groups and educational programs can empower individuals with PD and their caregivers. Research demonstrates that social seclusion links to increased disease impact and a decline in quality of life among individuals with Parkinson's disease. PwP might find themselves caught in a cycle where they



experience stigmatization and subsequently withdraw, leading to isolation. This isolation can further exacerbate both their motor and non-motor symptoms, perpetuating feelings of loneliness. Numerous studies highlight the value of a strong social network, as it can extend independent living, reduce health complications, and enhance individuals' ability to cope with chronic conditions. This is particularly relevant in PD, where social support has been demonstrated to reduce stigma, depression, and anxiety. Strong social connections correlate with improved emotional well-being, communication, and life satisfaction (Subramanian et al., 2023).

Given the individualized nature of symptoms in PD, a universal treatment approach is not applicable. Instead, interventions need to be personalized to match each individual's unique symptom profile. Recognizing the significant impact of non-motor symptoms and embracing a comprehensive and collaborative approach to care are essential in improving the quality of life for individuals with PD. This holistic strategy enables healthcare professionals and support networks to effectively address the multifaceted nature of Parkinson's, thereby enhancing overall well-being.



Additional Resources

Parkinson Disease: An Introductory Guide, Part 2 (page 66-114) [view guide]

Non-motor Symptoms | Dr. Keiran Tuck [view slides]

Physician Guide: Non-motor symptoms of Parkinson's Disease | R. Postuma MD, S. Rios

Romenets MD, R. Rakheja [view booklet]

References

- Berganzo, K., Tijero, B., González-Eizaguirre, A., Somme, J., Lezcano, E., Gabilondo, I., Fernandez, M., Zarranz, J. J., & Gómez-Esteban, J. C. (2016). Motor and non-motor symptoms of Parkinson's disease and their impact on quality of life and on different clinical subgroups. *Neurología* (English Edition), 31(9), 585–591. https://doi.org/10.1016/j.nrleng.2014.10.016
- Bock, M. A., Brown, E. G., Zhang, L., & Tanner, C. (2022). Association of Motor and Nonmotor Symptoms with Health-Related Quality of Life in a Large Online Cohort of People with Parkinson Disease. *Neurology*, 98(22), e2194–e2203. https://doi.org/10.1212/wnl.00000000000000113
- Fereshtehnejad, S.-M., Rodríguez-Violante, M., Martinez-Ramirez, D., & Ramirez-Zamora, A. (2021). Editorial: Managing Parkinson's Disease With a Multidisciplinary Perspective. *Frontiers in Neurology*, 12(799017). https://doi.org/10.3389/fneur.2021.799017
- Hermanowicz, N., Jones, S. A., & Hauser, R. A. (2019). Impact of Non-Motor Symptoms in Parkinson's disease. *Neuropsychiatric Disease and Treatment*, *Volume 15*, 2205–2212. https://doi.org/10.2147/ndt.s213917
- Ross, C. E., & Mirowsky, J. (2002). Family Relationships, Social Support and Subjective Life Expectancy. *Journal of Health and Social Behavior*, 43(4), 469. https://doi.org/10.2307/3090238
- Subramanian, I., Perepezko, K., Stone, B., Chaudhuri, R. K., & Pontone, G. M. (2023). Wellness in Parkinson's Disease: A Framework for Management Using a Holistic Culturally Sensitive Approach. *TouchREVIEWS in Neurology*, *19*(1), 8–13. https://doi.org/10.17925/usn.2023.19.1.8



- Todorova, A., Jenner, P., & Ray Chaudhuri, K. (2014). Non-motor Parkinson's: Integral to Motor Parkinson's, Yet Often Neglected. *Practical Neurology*, *14*(5), 310–322. https://doi.org/10.1136/practneurol-2013-000741
- Zis, P., Erro, R., Walton, C. C., Sauerbier, A., & Chaudhuri, K. R. (2015). The range and nature of non-motor symptoms in drug-naive Parkinson's disease patients: a state-of-the-art systematic review. *Npj Parkinson's Disease*, 1(1).

https://doi.org/10.1038/npjparkd.2015.13