Parkinson Association of Alberta *Quarterly Magazine* Summer 2026

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Message from our Executive Director

Dear friends,

As summer unfolds across Alberta, I am pleased to welcome you to another edition of Pulse, Parkinson Association of Alberta's quarterly magazine for our community.

This issue explores a topic that many people living with Parkinson disease, care partners, and families know well: the questions that do not always make it into the doctor's office. The unusual symptoms. The unexpected experiences. The "Is this normal?" moments. The questions that can feel too odd, too specific, or too difficult to ask.

Parkinson disease is complex, and no two journeys are exactly alike. Along the way, many people encounter experiences that leave them searching for answers and wondering if anyone else has faced the same challenges. Through this edition, we hope to shed light on some of those lesser-known questions, share insights from experts and community members, and remind you that curiosity is an important part of understanding and managing Parkinson disease.

As we look ahead to the months of summer, I am filled with gratitude for the incredible support and engagement of our community across Alberta. This season offers many opportunities to gather, connect, and enjoy time together. Our social gatherings continue to create space for friendship, shared experiences, and meaningful conversations, reminding us that community remains one of our greatest strengths.

This summer also marks a significant milestone as we celebrate the 10th anniversary of the Buchanan Centre in Edmonton. For a decade, the Centre has served as a welcoming place where people feel understood, valued, and supported. It has become a home for individuals living with Parkinson disease, people with acquired brain injuries, community organizations, families, volunteers, and countless others who have walked through its doors. The anniversary is a wonderful opportunity to honour the vision of Gordon and Diane Buchanan, the original investors, and everyone who helped transform that vision into a lasting legacy for our community.

None of this would be possible without the generosity and dedication of so many people. To our volunteers, thank you for the time, compassion, and energy you contribute every day. To our donors, thank you for investing in programs, services, education, and research that make a meaningful difference in people's lives. To everyone participating in, sponsoring, or supporting Step 'n Stride, thank you for helping raise awareness and critical funds that allow us to continue serving Albertans affected by Parkinson disease. Your commitment strengthens our mission and helps ensure that no one must face Parkinson disease alone.

As you read through this issue, I encourage you to remember that there are no dumb questions. If you are experiencing something that does not seem to fit the textbook description of Parkinson disease, if you are struggling to find reliable information, or if you simply need someone to help navigate uncertainty, please reach out. Our team is here to listen, connect you with resources, and help you find answers—or at least help you know where to begin looking.

Thank you for being part of this remarkable community. Together, we continue to learn, support one another, and discover new possibilities on the Parkinson journey.

Wishing you a safe, enjoyable, and connected summer season.

Lana

THE WEIRD ONES

Written By Brandi La Bonte

At Parkinson Association of Alberta our small, but mighty Team meets and provides information, support, and offerings for a lot of people with Parkinson's (over 35,000 in the last three years alone!!); and do you know what the most common beliefs people have about Parkinson's is?? **That everyone experiences Parkinson disease in the same way.** This is one of the biggest misconceptions and could not be further from the truth. In fact, like tiger or zebra stripes, fingerprints, or snowflakes every person's experience with Parkinson disease is unique. So unique in fact, that there is a saying in the Parkinson's community that "**If you've met one person with Parkinson's, you've met ONE person with Parkinson's.**"

This simple phrase highlights the unpredictable and unique nature of Parkinson disease, where no two journeys are the same. Parkinson disease is a complex condition and unique to the individual on many levels – from early signs to diagnosis, treatment options, progression, and of course presentation of symptoms. The uniqueness of Parkinson's means that not all people who have Parkinson's will experience all the symptoms (both motor and non-motor), and the progression/ severity of those symptoms vary from person to person.

Symptoms in Parkinson's are, in general, divided into two categories: motor and non-motor.

There are four main Parkinson's **motor symptoms** are:

- **Tremor –** an involuntary trembling or shaking that can appear in a hand, fingers, or leg on one side when they are just resting, this will eventually move to both sides. (IMPORTANT NOTE: Not everyone with tremor has PD and not everyone who has PD has a tremor.)
- **Slowed movement (bradykinesia) –** when it comes to moving everything is slowed down and it takes more of an effort. Over time, movement may slow, making simple tasks difficult and time-consuming. Steps may become shorter, and feet may drag when walking. It may be difficult to get out of a chair, off a bed or out of a car.
- **Rigidity –** stiffness of muscles, usually detected by your doctor or health care team.
- **Difficulties with walking and balance –** footsteps get smaller resulting in a more shuffling gait instead of traditional strides; and a stooped posture may be present when walking – both of which can impede balance.

In addition to motor symptoms, there are a host of other symptoms that do not affect movement and are much harder to see. These are known as non-motor symptoms and they encompass a wide range of health concerns such as autonomic dysfunction (constipation, temperature regulation, sexual dysfunction, etc.), speech/ swallowing issues, sleep issues, and thinking and psychological changes.

As unique as Parkinson's is, the above-mentioned symptoms are fairly common and/or well-known within the Parkinson's community. But what happens when you experience something that no one else seems to be? Navigating elusive symptoms has the potential to bring about feelings of frustration, anger, and even fear. It can leave a person feeling even more isolated and alone. But there is most definitely hope.

First, there are over 10 million (and rising) people living with Parkinson's on this planet, it is inevitable that someone, somewhere is also experiencing the same thing – including the frustration, fear, and isolation. The tricky part is the planet is huge; and closer to home, Aberta and the Northwest Territories are massive with people spread out over 661,848 and 1,346,106 square kilometres

respectively. Depending on where you live, it can be hard to find other people with Parkinson's let alone someone experiencing the exact same thing you are; but that doesn't mean someone isn't.

Second, researchers, medical professionals, and even staff at PAA are always learning new things about Parkinson disease and Atypical Parkinsonism. It takes time, but research moves forward, technology in the medical field changes, and our collective knowledge grows and evolves.

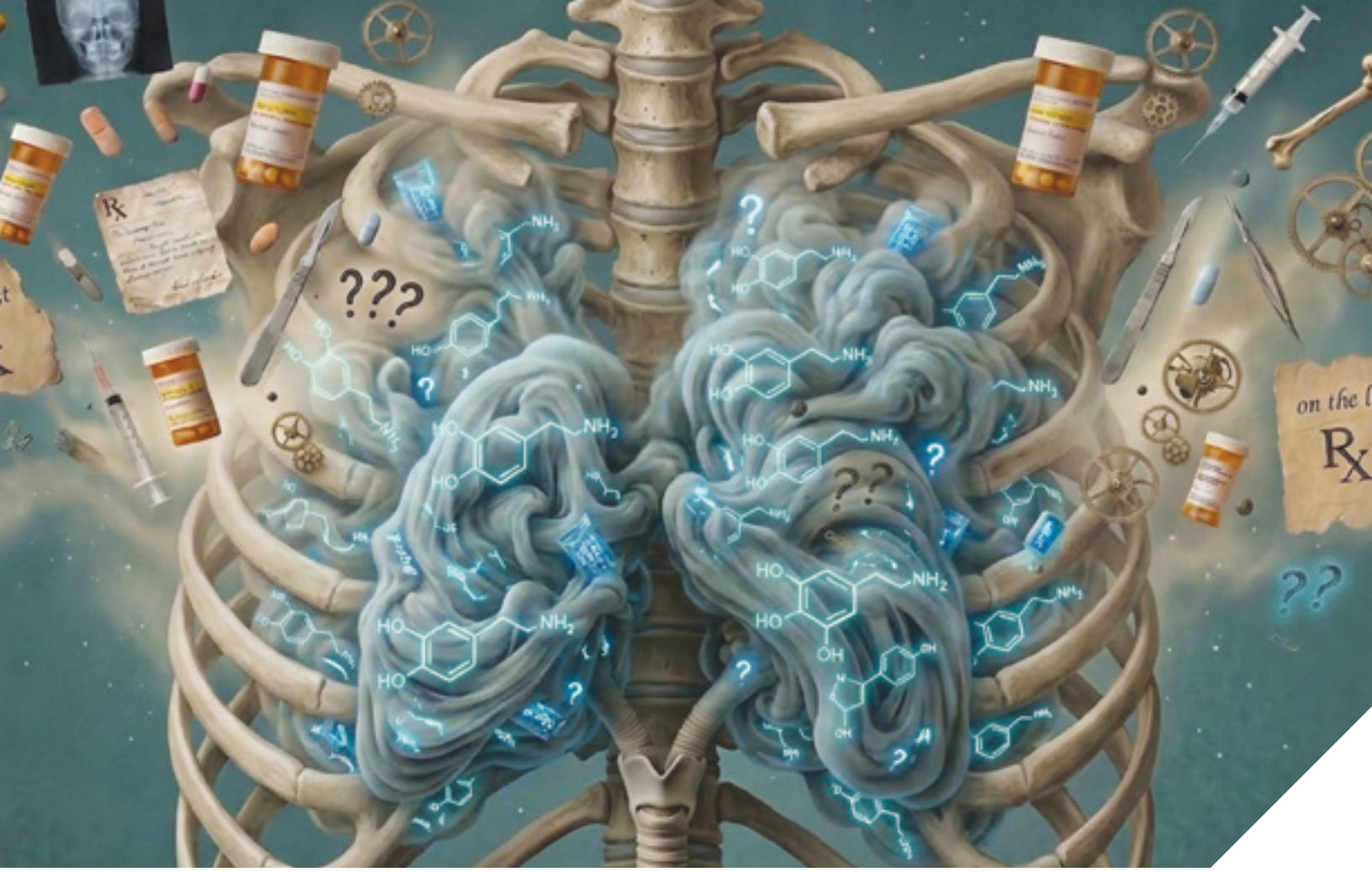
Finally (and most importantly) YOU! When people impacted by Parkinson's share not only their experiences but their new, weird, or seemingly strange phenomena with others (including PAA staff) the more we can connect the dots, connect with others, and the more we all learn!

We have an informal motto of sorts here at PAA that goes "When we know better, we do better." You may have heard us at one time, or another respond to an asked question with "Hmmm, that's a great question, I'm not sure. Let me go do some digging and I'll get back to you." And off we go to see what we can find out. The folks who were brave enough to share their non-traditional symptoms were the inspiration for this issue. Every article in this issue came about because someone was experiencing something outside the "ordinary" and shared their challenges with us.

So, what can you do if you are experiencing a symptom that seems to be outside of the norm? First and foremost, share your concerns with medical professionals. This can sometimes feel frustrating because if symptoms don't "fit" a traditional diagnosis (like Parkinson's), your concerns may be discounted or disregarded. To help you better explain what you are experiencing to your health care professional you may want to consider doing the following:

- **Track the Symptoms:** Similar to explaining pain (Spring 2026 issue) record exactly when the symptoms occur, how are they presenting, what makes them better or worse, were you doing anything before the symptom occurred (ie: sleeping, exercising, eating, etc.).**Track the Timeline:** Does the timing of your symptoms have a pattern? Or is it random? Tracking over time will help determine if there is a pattern/connection.**Don't Edit the Details:** Often people will leave out things that they feel are silly, or unimportant. What may seem unconnected to you, might be a key clue to a medical professional.*Other steps that may help:*
- **Not all primary care providers are going to be able to help you themselves, they may refer you to a specialist for a consult or you may have to request one yourself.**
- **Reach out to Parkinson Association of Alberta, with our deep network of clients (and their experiences), medical professionals, and other stakeholders, we are willing, ready, and able to provide insight and help however we can.**

So, whether you are experiencing any of these "weird" symptoms, have different "weird" symptoms, or just have "regular", run-of-the-mill Parkinson's symptoms we hope this issue not only provides insight and information, but also serves as a reminder that Parkinson Association of Alberta is here for you and all of the weird and wonderful experiences you may encounter on your journey. ■



BREATHING

The Parkinson's Plot Twist

Written By Candice Mandin

The first step is always to rule out other causes by having your heart and lung function checked.

Have you ever felt short of breath from just crossing the room or even while sitting at rest? Maybe you have noticed it feels difficult to take a deep breath. Could this be related to Parkinson's disease (PD)?

Trouble breathing is not usually the first thing people think of when it comes to Parkinson's. The first step is always to rule out other causes by having your heart and lung function checked. People with PD can still develop health issues that are not related to PD. But if other causes are ruled out, PD itself can sometimes contribute to breathing difficulties. Let us go over some of the more common issues that might happen and then we will talk about what can be done to help manage them.

So, what is going on?

Dopamine helps all muscles move smoothly, not just the big ones in your arms, legs, or core. Think about all the muscles involved in breathing: the chest wall, the muscles between the ribs, and the diaphragm all play a key role. When the brain does not have enough dopamine, these muscles do not work as efficiently.

Common Respiratory Issues in Parkinson's:

Restrictive Respiratory Dysfunction:

Basically, means your breathing muscles have become slower or stiffer, so your lungs can not fill up as much as they normally would. On top of that, things like a stooped posture, head drop, leaning to one side, or bending at the waist can make it even harder to take a full breath.

Shortness of Breath (Dyspnea):

People often describe it as a tight feeling in the chest, like you just can not get a deep breath or that breathing suddenly takes a lot more effort. It can show up when you are resting or when you are active, like during exercise or any more demanding activity. Sometimes it happens when medication is "wearing off," meaning symptoms start creeping back before the next dose. The breathing muscles can get stiff or not work smoothly, which leads to that shortness of breath. Anxiety, another common symptom of PD, can make the whole thing feel even worse.

Respiratory Dyskinesia:

Dyskinesia is involuntary muscle movement. This can happen to larger muscle groups in the body and can also impact the muscles that help with breathing. Respiratory dyskinesia looks like irregular, rapid breathing and is often linked to when levodopa medications reach their peak effect. You might be experiencing uncontrolled or 'surprising' sharp breaths in or out. Fluctuations in the effectiveness of levodopa tends to happen more frequently the longer a person lives with PD and can contribute to dyskinesia. Something to keep in mind is that the irregular breathing that occurs with respiratory dyskinesia can raise your risk of choking or inhaling food or liquids. If trouble breathing involves severe confusion, dizziness, loss of consciousness or causes significant fear or anxiety, it is crucial to seek medical advice immediately.

Upper Airway Obstruction (UAO):

We mentioned earlier the importance of the neck and throat muscles in breathing. When these muscles are affected by a lack of dopamine, upper airway obstruction (UAO) can happen. Symptoms can include hypophonia (a soft or quiet voice), a shaky voice, stridor (noisy or rattly breathing), or wheezing, sometimes caused by a narrowed airway.

There are two main types of UAO1:

1. Respiratory flutter – This is like a resting tremor in the airway and leads to a partial reduction in airflow. It can feel like a trembling or vibrating feeling when you breathe in. It can also feel like breathing that comes in quick little bursts or pulses.
2. Intermittent airway closure – In this type, irregular, jerky movements of the vocal cords and surrounding muscles (including some involved in swallowing), can temporarily block the airway. It feels like your breathing gets blocked for a moment, like a doorway suddenly closing and then reopening. It can cause short pauses in breathing, gasping, coughing, or a feeling of tightness that comes and goes.

Phlegm buildup and impaired coughing (dystussia):

Parkinson's can also cause a buildup of phlegm and mucus due to less effective swallowing, coughing, and clearing of the throat. This can make it feel like you need to clear your throat or cough more often; your voice might feel wet or "gurgly." It is important to see a specialist (respiratory or speech therapist) to address this to reduce the risk of aspiration and aspiration pneumonia.

Sleep Apnea:

Parkinson's can be associated with sleep apnea, a disorder where breathing stops and starts during sleep, leading to low oxygen levels. Again, the muscles in the neck and throat can be affected by a drop in dopamine levels, notably at night when medications may be wearing off.

Aspiration Pneumonia:

People with PD are at higher risk of pneumonia, particularly aspiration pneumonia, where food or liquid enters the lungs. This happens when the protective mechanism, the epiglottis (that dangly bit at the back

of the throat), fails to block the trachea (windpipe) during swallowing. You might have heard someone say: “it went down the wrong pipe.” The inhaled material can carry bacteria, leading to lung infections.

What can help?

Breathing exercises. Strengthen and stretch your chest muscles, intercostal muscles (muscles between the ribs) and diaphragm to help increase lung capacity.

- Belly breathing (consciously breathing into your stomach to stretch and strengthen your diaphragm).
- Triple-part breathing: Sip your breath in three parts with a pause at the top of the inhale. Exhale slowly and divide the exhale into three parts.
- Box breathing – Inhale 4 counts, hold 4 counts, exhale 4 counts, hold 4 counts.

Being mindful of posture: Doing exercises to make sure your posture is straight, and shoulders are not curving in around our chest cavity. The stooped posture makes it much harder for your lungs to fill with air as it shrinks the space available for the lungs to inflate.

Medication adjustments: Your health care provider (typically your neurologist) will assess if there is a need to adjust levodopa dosages/timings or add a medication like a COMT inhibitor or amantadine to help manage respiratory dyskinesia.

Managing anxiety through counseling therapy and/or prescribed medication. This can help manage breathing difficulties tied to anxiety. You can speak to your doctor to see if prescription medication is appropriate for you or reach out to a local therapist to discuss if counseling is a good fit for you.

Respiratory therapists and speech-language pathologists: They can help you strengthen respiratory and swallowing muscles, improve your breathing patterns and airflow control, and teach you strategies to reduce the risk of complications like aspiration and pneumonia. Ask your doctor for a referral to access one of these specialists.

EMST device (Expiratory Muscle Strength Trainer) This is like a tiny gym for your lungs. It is a small device that helps strengthen muscles to improve breathing, cough, swallowing, and speech by creating resistance when breathing out of the device. There are also inspiratory (inhale) attachments available. It is adjustable so you can change the resistance throughout your training. You can purchase these online or at medical supply stores. You can ask your speech or respiratory therapist for instructions and there are also detailed training videos available online to teach you how to use one.

Sleep Apnea machine to help make sure you get enough oxygen at night. It is often called a Continuous Positive Airway Pressure (CPAP) machine. The process to get one starts with an assessment by a healthcare provider for diagnosis and then referral for a sleep study. After receiving a prescription for the device, you can purchase through a retailer, and coverage may be available through insurance Many CPAP providers also offer payment plans to make the cost more manageable.

Experiencing respiratory issues can be distressing and navigating them starts with identifying what is occurring. You are not alone if you are experiencing respiratory changes in Parkinson’s’ and most importantly support exists to help you feel more like you. ■

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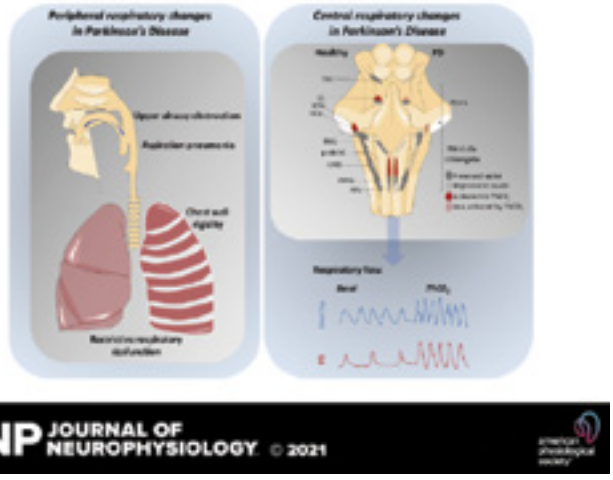
Diagram retrieved from JNP Journal of Neurophysiology https://journals.physiology.org/doi/full/10.1152/jn.00363.2021



DYSKINESIA

A Double-Edged Sword

Written By Charlene Heavener

Do you find you have extra movement, involuntary movement you cannot seem to stop? Do you feel you switch between stiffness and too much movement? Then you might be experiencing dyskinesia. You may have heard the words dyskinesia or diphasic/biphasic dyskinesia. You might be thinking these are hard words to pronounce and even harder to describe.

So, what is dyskinesia? In basic terms it is abnormal, involuntary, purposeless movement. It can involve your limbs, trunk, head, neck, facial muscles, mouth or even tongue. This movement is different from a tremor which is described as a rhythmic type of movement. Dyskinesia can be related to both disease progression and medication, or a combination of both. As Parkinson's progresses, motor fluctuations increase and are a result of the brain's declining ability to store and release dopamine consistently. Parkinson's medications like levodopa carbidopa help replace dopamine, however, over time the brain's lack of dopamine leads to more inconsistent symptom management, leading to peaks and valleys in symptom control and dyskinesia. For some people, especially those diagnosed at a younger age, years of levodopa use can also increase the likelihood of developing dyskinesia.

Peak dose dyskinesia is the most common type. These typically occur when medications are working at their peak or best to control motor symptoms. This time frame of when medications are working is often referred to as the ON period. These movements have been described as twisty, bouncy and writhing movements. If one was to plot this on a graph it would look like a roller coaster: going up represents the medications starting to work and the dyskinesia occurring and then coming down represents when the medications are starting to wear off and the dyskinesia subsiding.

Diphasic or biphasic dyskinesias are more rare than peak dose dyskinesia and can occur as the "ON" starts and AGAIN as the "OFF" starts. These movements have been described as jerky like movements.

They can be more difficult to describe, and this form of dyskinesia is often harder to manage.

Diphasic/biphasic dyskinesia often appears when levodopa levels are changing rather than when they are at their highest, which is one reason it can be tricky to recognize. As these are more uncommon and movement is similar yet different from peak dose dyskinesia it can sometimes help to record videos of these movements to show health care professionals. Taking a series of videos at specific times when the movements are happening with the mention of the time in relation to when was the last dose of medication can be very helpful. This can help in diagnosis and help differentiate the movements from peak dose dyskinesia.

Dyskinesia is different for everyone; it can range from mild and unbothersome to severe where it has an impact on everyday life. This includes making some activities more challenging when someone is unable to control the movements. Activities like getting dressed, putting on make-up, brushing teeth, shaving, eating. It can also affect other leisure activities like going to a movie, out to eat, reading a book. For some it impacts them during times when moving is not ideal such as at the dentist, getting a haircut, or having an x-ray just to name a few. Dyskinesia can also have social impact. It can feel embarrassing when people are staring or pointing or worse when one must explain why they are moving around in "that way." Dyskinesia can also cause pain and discomfort from the additional movement. This might feel like tightness, burning or joint pain.

Another important consideration is unintentional weight loss. Movement burns calories and some people with dyskinesia find they start to lose weight and struggle maintaining or gaining back weight due to this additional movement. Maintaining a healthy weight is important and when this weight loss is occurring in an uncontrolled way where weight is getting low the intake of additional calories or healthy higher calories foods may be considered to help with management. A registered dietitian or your health care provider can help explore options for maintaining weight in a safe and healthy way.

Dyskinesia can be a double-edged sword, where there is a fine line of balance between stiffness and rigidity and too much movement. For many people with Parkinson's, they would prefer to be able to move even if it is dyskinetic type of movement, rather than be stuck or frozen or unable to move.

Management of dyskinesia will depend on the type of dyskinesia and how dyskinesia impacts daily life. As individuals experience with dyskinesia varies and management can be challenging the goal is to maintain good movement and mobility while reducing or limiting dyskinesia. If this abnormal movement is impacting your everyday life, then it needs to be discussed with your health care provider. Sometimes it may mean adjusting Parkinson's medications, sometimes it may mean adding a medication like amantadine to help control some of these extra movements, sometimes it may be a discussion about other potential options for symptom control like Duodopa or Deep Brain Stimulation. Both of which may be able to reduce dyskinesia for some individuals. Alongside medication adjustments, some people also find that certain lifestyle approaches can help reduce the impact of dyskinesia. These may include gentle, rhythmic exercise such as walking or stretching to help settle excess movement, planning activities during more predictable ON times, reducing stress where possible (as stress can sometimes amplify movement), and pacing daily tasks to avoid fatigue. Staying hydrated, maintaining regular meals, and keeping a consistent medication schedule can also support steadier motor control. While these strategies do not eliminate dyskinesia, they can help make daily life feel more manageable. In many cases, a combination of medication changes, advanced therapies, and lifestyle strategies (such as timing activities around ON periods) can offer the best balance.

Dyskinesias can be challenging to treat but often more difficult to live with. It is not as simple as "just stop moving!" ■

PARKINSON

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SATURDAY SEPTEMBER 19TH

- **COCHRANE**
  Historic Cochrane Ranche - 9AM
- **LETHBRIDGE**
  Henderson Lake Park - 9AM
- **OLDS**
  Rotary Athletic Park - 9AM
- **RED DEER**
  Canada 150 Square at Capstone - 9AM
- **LLOYDMINSTER**
  Bud Miller Park - 1PM

SUNDAY SEPTEMBER 20TH

- **EDMONTON**
  Rundle Park - 9AM
- **CALGARY**
  South Glenmore Park - 1PM
- **CAMROSE**
  Grand Drive Park - 1PM
- **GRANDE PRAIRIE**
  South Bear Creek - 1PM

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ACROSS

2. Group of people who find belonging with one another

3. An activity that takes place before walking

4. The team that helps support Step 'n Stride

5. The month Step 'n Stride takes place

DOWN

1. The summer event held for Step 'n Stride communities to socialize

6. The Step 'n Stride location that resides outside Alberta

7. The number of Step 'n Stride locations

8. The theme for Step 'n Stride 2026

9. The main colour featured in this year's theme

10. The goal of Step 'n Stride is to spread _____

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PERSONALITY & MOOD CHANGES IN PARKINSON'S

Don't Let It Change Who You Are

Written By Brienne Leclaire

When most people think of Parkinson disease, they picture the visible signs, a tremor in a hand, stiffness in a shoulder, a slower, more deliberate walk. But for many with Parkinson's and their families, the most profound changes are the ones that cannot be seen so easily. They show up in the tone of a voice, the spark in a conversation, the way a person reacts to stress or expresses emotion. These subtle shifts in personality and mood can be among the most confusing parts of the Parkinson's journey, especially because they do not always come from the same place. Some arise from the disease itself; others emerge from the treatments that help manage it.

Understanding these changes does not just help families make sense of what they're seeing. It helps protect relationships, reduce conflict, and preserve the sense of connection that Parkinson's can sometimes strain.

The Brain

Parkinson's is often described as a movement disorder, but that's only part of the story. The same dopamine pathways that help coordinate movement also shape motivation, impulse control, emotional expression, and the ability to adapt to stress. As dopamine levels decline, the brain's emotional circuitry shifts and as medications or surgical treatments work to replace dopamine or modify brain activity, we see can shift again. These changes are not choices; they are not character flaws. They are neurological symptoms that are real, measurable, and deeply tied to the biology of Parkinson's.

What Changes?

One of the earliest and most misunderstood changes is a softening of emotional expression. A person who once smiled easily may now appear serious or distant, even when they feel perfectly content. Their voice may lose its natural rise and fall. Their gestures may become smaller, less animated. Families often describe this as a "mask," and that's exactly what it is: a motor symptom that hides emotion rather than reflecting it.

This mismatch between how a person feels and how they appear can create tension. A spouse may interpret the stillness as disinterest. A friend may assume irritation where none exists. Meanwhile, the person with Parkinson's may feel misunderstood, or even blamed for something they can't control.

Other changes unfold more gradually. Someone who once handled chaos with ease may now feel overwhelmed by noise, clutter, or unexpected changes in routine. Irritability can surface where patience once lived. The brain's ability to filter stress becomes less flexible, and small frustrations can hit with surprising force. Changes in cognition, stress and emotional thresholds can lead to these shifts in personality and

emotional regulation. These can also lead to some people become more emotionally sensitive, for example moved to tears by moments that never would have stirred them before. Others become more blunt or less inhibited, speaking more directly or reacting more quickly than they once did. These shifts do not erase a person's core personality, but they can tilt the balance of traits that were already there or cause shifts in personality that differ from who one once was.

Parkinson's Medications can restore movement, ease stiffness, and bring back a sense of fluidity in daily life. But because dopamine also fuels the brain's reward and motivation pathways, these same treatments can sometimes create emotional or behavioural changes that feel out of character. Some people develop impulse control disorders. This includes behaviours like compulsive gambling, overspending, binge eating, or repetitive, almost mechanical hobbies. Others experience a lift in mood that goes beyond feeling good, a burst of energy, talkativeness, or optimism that feels more like a chemical surge than a personality shift. Still others describe a sense of emotional flatness, as though the volume has been turned down on their inner world.

Then there are the fluctuations. As medication levels rise and fall throughout the day, mood and personality can ebb and flow with them. A person may feel irritable or restless before their next dose, then more confident or outgoing once the medication takes effect. These cycles can be predictable at times, but they can also be unpredictable as medications fluctuate.

Deep Brain Stimulation (DBS) is a powerful tool available for managing Parkinson's symptoms. For many people, it brings remarkable improvements in tremor, stiffness, and movement fluctuations. But because DBS works by altering electrical activity in the brain's motor circuits and because those circuits sit close to regions involved in emotion, impulse control, and personality DBS can sometimes shift the emotional landscape as well. Most people experience no significant personality change. But for a small subset, DBS can subtly alter how they respond to the world. Some individuals describe feeling more impulsive or more emotionally reactive after surgery. A few experience changes in social behaviour, becoming more talkative or more withdrawn. These shifts are usually mild, but they can feel startling to families who know the person well.

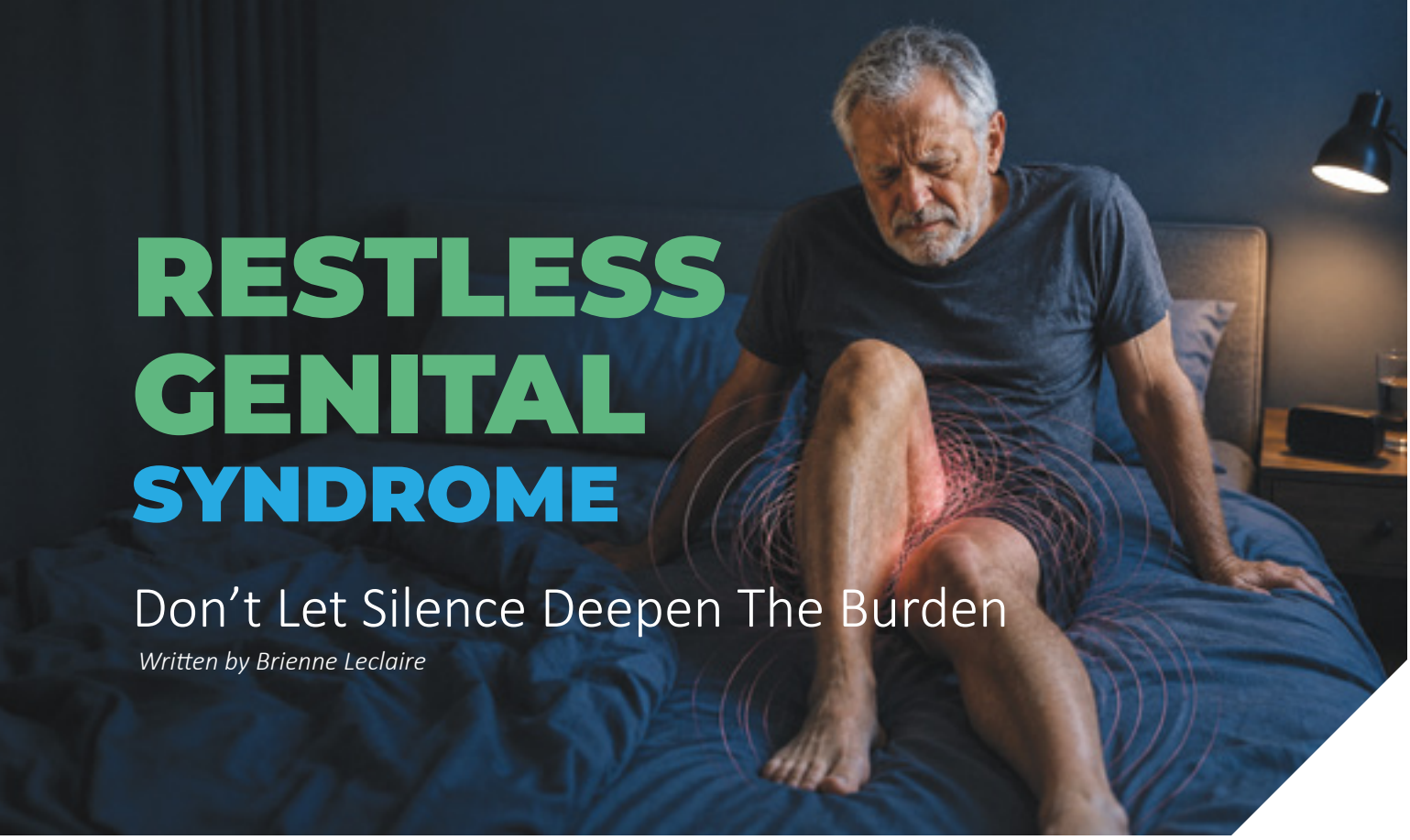
Occasionally, the stimulation settings themselves play a role. A slight adjustment in the electrical parameters can sometimes ease an unwanted emotional change, just as it can finetune movement symptoms.

Management and Supports

Personality changes in Parkinson's are treated by first identifying what's driving them whether it's the disease itself, medication effects, or changes related to Deep Brain Stimulation. Treatment often involves adjusting Parkinson's medications to smooth out irritability, impulsivity, or emotional fluctuations, or fine-tuning DBS settings if stimulation is affecting mood or behaviour. When medication related impulsive behaviours appear, reducing or changing the drug often leads to meaningful improvement. Counselling, occupational or speech therapy, and education for families can also help people manage emotional sensitivity, lowered stress tolerance, or changes in expressiveness. While the exact approach varies, many personality related changes improve once the underlying cause is addressed, especially with coordinated care from a health care provider and supportive strategies at home.

For families, the most important step is recognizing that these shifts reflect the brain's evolving chemistry and circuitry, not a change in love, loyalty, or character. Open conversations help. So, does tracking patterns, when do changes appear? Do they follow medication timing? Stress? Fatigue? Stimulation adjustments? These observations give healthcare providers the information they need to fine tune treatment.

Above all, compassion matters. Approaching these changes with curiosity rather than judgment protects dignity and preserves connection. It allows families to stay on the same team, even when the emotional landscape feels unfamiliar. Parkinson's may alter how a person expresses themselves or responds to the world, but it does not erase who they are. With understanding, support, and thoughtful care, individuals and families can navigate these shifts while holding onto the heart of their relationships and to the person beneath the symptoms. ■



RESTLESS GENITAL SYNDROME

Don’t Let Silence Deepen The Burden

Written by Brienne Leclaire

Restless Genital Syndrome (RGS) is a rare condition characterized by persistent, unwanted genital sensations that are similar to arousal signals but are not linked to sexual desire. These sensations can feel invasive, upsetting, and even confusing. For those experiencing RGS, it can add another layer of challenge to an already complicated neurological condition. Because the symptoms are intimate and often misunderstood, many with RGS hesitate to speak up, leading to feelings of isolation. Yet putting a name to the problem and learning how it works are the first steps toward getting help and finding relief.

The cause of Restless Genital Syndrome in Parkinson disease is not fully understood. Several factors may contribute to its development. Parkinson’s changes the brain’s dopamine system, which is central to both movement and sensory regulation. These changes can alter how the nervous system processes movement and sensations, sometimes leading to unusual or intrusive sensations. In addition, medications commonly prescribed for Parkinson disease can affect sexual function and sensory pathways, occasionally triggering symptoms like RGS. However, these may also be used to reduce symptoms of RGS. Researchers also note that RGS shares very similar features with restless legs syndrome, suggesting that similar neurological factors may be involved in its development.

What does RGS look like? RGS typically presents with a range of symptoms that can be both physically uncomfortable and emotionally draining. People may experience tingling, throbbing, or pressure in the genital area, sensations that mimic arousal but occur without desire or stimulation. These feelings often worsen during periods of rest or inactivity, similar to restless legs syndrome. Sleep disruption is common, as sensations can worsen at night. Beyond the physical discomfort, the emotional impact is significant, embarrassment, frustration, and anxiety often accompany RGS symptoms. Because symptoms are in such a sensitive and intimate area, many delay seeking help due to embarrassment or stigma, which can compound distress and delay treatment.

Managing RGS in Parkinson disease requires an individually tailored approach. The first step is typically reviewing current medications. Adjusting doses or switching medications may help reduce symptoms for some people. Dopamine agonists like pramipexole and ropinirole are sometimes prescribed to reduce symptoms, though can also in turn be the cause of RGS for some. Medications for treating

similar syndromes, such as restless legs syndrome, may also offer support for some individuals. These may include gabapentin, propranolol, tramadol, and others. Pelvic health physiotherapy offers another avenue, focusing on muscle tension and improving comfort in the pelvic region. Psychological support is equally important, helping individuals cope with the emotional effects of persistent sensations and develop coping strategies to ease symptoms. While there is no single treatment, combining medical, physical, and emotional approaches can make symptoms more manageable.

Living with RGS can feel overwhelming, but practical strategies can help reduce its impact:

- Gentle movement or stretching may ease sensations, echoing strategies used for restless legs syndrome.
- Relaxation techniques such as mindfulness, meditation, or breathing exercises can calm the nervous system and reduce distress.Maintaining good sleep hygiene with consistent routines, a cool and quiet environment, and limiting stimulants can minimize nighttime symptoms.
- Finding relaxing activities one enjoys, such as reading, listening to music, or engaging in light activity, can redirect focus away from discomfort.
- Most importantly, open communication with healthcare providers ensures that symptoms are acknowledged and addressed rather than hidden.

Support for RGS in Parkinson's comes from multiple sources. Neurologists, especially movement disorder specialists, are central to managing the rare condition, because they know how Parkinson's affects both movement and sensation. As well as can manage medications for both Parkinson's and RGS. Pelvic health physiotherapists can provide targeted exercises and interventions to ease discomfort. Mental health professionals offer coping strategies for the emotional impact, helping individuals navigate embarrassment and anxiety. Parkinson Association supports also play a role, offering safe spaces to share experiences and learn from others. Knowing that help exists and that others have faced similar challenges can help one feel less isolated.

Restless Genital Syndrome in Parkinson disease is rarely discussed, but silence only deepens the burden. By naming the condition, exploring its causes, and seeking support can help one reclaim a sense of dignity and control. RGS reminds us that neurological disorders affect far more than movement they touch every aspect of the human experience, including the most private. In the end, the message is clear, no symptom is too small, too strange, or too embarrassing to not deserve care. Talking about RGS is the first step toward relief, and relief is possible. ■

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A WHOLE LOTTA SHAKIN' GOING ON

Tremors In Weird Places

Written by Cherlene Magnuson

We are all familiar with physical When most people think of Parkinson's disease (PD), they picture a hand that shakes at rest. The classic tremor image that has come to define Parkinson Disease in the public eye. But anyone living with Parkinson's knows the truth is far messier, far more complex… and yes, sometimes far weirder than that.

Parkinson's tremors are not just confined to the hands and feet. Some days, it can feel like the King himself- Elvis- has taken up residency in your nervous system, with a "whole lotta shaking going on." Tremors can show up in the jaw, tongue, lips, eyes, ears, chest, pelvis, genital region, and even deep inside the body where nothing is visible, but everything is felt.

These subtle tremors may not demand attention the way Elvis's Adonis jumpsuits once did, but for the person experiencing them, they can dominate every part of their day.

Imagine a tremor in your jaw that makes chewing painful. Or a tongue that refuses to cooperate when you try to form words, a constant vibration in your chest that no one else can feel, or an annoying flutter in your ear. Now imagine that sensation lingering all day, every day.

What Is a Parkinson Tremor?

A Parkinson tremor has several defining features:

- **At rest:** Most noticeable when the body is at rest, often easing with purposeful movement, holding an object like a glass of water or something weighted.
- **Asymmetrical:** Parkinson tremors typically begin on one side of the body, especially in initial stages, and may progress to both sides as the disease progresses.
- **Rhythmic:** meaning they are usually smooth, slow, and continuous rather than sudden jerks or spasms.
- **Elevated when stressed:** Anxiety, fatigue, and emotional strain can intensify tremors, making already challenging moments even harder.

While hands and feet are the most affected areas, Parkinson tremors do not always follow the rules. Recognizing tremors in less typical locations is essential for early intervention, appropriate care and quality of life.

Types of Tremors:

Internal Tremors: Some tremors are invisible to the outside world. Think of an iceberg: the tip is visible, but most of it remains hidden below the surface. Internal tremors may feel like vibrating, buzzing, or shaking inside the chest, abdomen, or limbs. They can make sitting, standing, or trying to sleep feel unsettling. Because no one else can see them, people often feel isolated or dismissed, as if their experience is not "real enough" to be understood.

Orofacial and Tongue Tremors: PD may affect facial muscles, causing tremors in the chin, lips, jaw, and tongue. Everyday acts like eating and speaking become exhausting. Words may stumble or be difficult to form, and chewing can take twice as long. Adding sleep bruxism (grinding or clenching teeth at night) can take a toll on dental health: jaw pain, worn teeth, headaches, and disrupted sleep leave people drained before the day even begins.

Pelvic and Genital Tremors: Though rarely discussed, tremors can occur in the pelvic or genital region. These can affect comfort, intimacy, and confidence. Open conversations with healthcare providers and pelvic floor therapy can make a meaningful difference.

Foot and Leg Tremors: Tremors in the legs or feet may appear when standing or during movement. Balance can feel uncertain, walking may feel precarious, and tasks that once required no thought suddenly require more planning, patience, and trust.

Ear Tremors: Tiny muscles inside the ear can flutter, creating vibrations or faint noises. Hearing is rarely affected, but the sensation can be unsettling, especially in quiet moments or before sleep.

Eye Tremors: Subtle tremors in the eyes can make reading, watching television, driving, or focusing on a screen uncomfortable and tiring.

Typical vs. Non-Typical Tremors

Not all tremors behave the same, and every Parkinson journey is unique. Classic resting tremors often respond well to medications like Levodopa. Tremors in unusual locations, however, may not improve and may sometimes persist or change, signaling the need for further evaluation or adjustments to treatment. Recognizing the difference allows healthcare teams to respond with precision and compassion.

Why Do These Tremors Occur?

Several varying factors contribute to tremors appearing in unexpected areas - and they are not always as straightforward as they seem.

- **Decline in dopamine:** Dopamine is the brain's chemical messenger that helps coordinate smooth, coordinated movement. When dopamine levels drop, signals between the brain and muscles misfire, allowing tremors to appear not only in the hands but also in the jaw, tongue, chest, pelvic region, or deep inside the body.
- **Stress, fatigue, and poor sleep:** These act like fuel on an already sensitive system. A rough night, a long day, or emotional stress can intensify tremors, making them feel stronger or more noticeable.
- **Medication timing:** Parkinson's medications rise and fall naturally throughout the day. During OFF periods, tremors can reappear or intensify. Sometimes they show up in unfamiliar places or feel different from the usual, simply because the brain is not getting consistent dopamine support.

These factors, changes in brain chemistry, daily stressors, sleep quality, and medication cycles, work together to shape how, when, and where tremors appear. While they may seem unpredictable from the outside, understanding these factors helps explain what people living with Parkinson's experience every day.

The Management

Across all these "weird" tremors, one thing remains constant: they disrupt life. Sleep, meals, conversations, mobility, independence, confidence, it all takes a hit. Managing these tremors is rarely a one-person job.

- Neurologists to assess tremor patterns and fine-tune medications.
- Dentists to manage bruxism and oral health.
- Physical and Occupational Therapists to support movement and mobility.
- Pelvic Floor Therapists for pelvic tremor management.
- Sleep Specialists for disrupted sleep cycles.
- Mental Health Professionals for anxiety, stress, and emotional support.
- Being kind to yourself is also, medicine.

When to Talk to Your Doctor

Consider reaching out if you notice:

- New or worsening tremors
- Tremors in unusual locations
- Tremors interfering with daily life, speech, sleep, or mobility.
- Changes in how symptoms respond to medication.
- Emotional distress or social withdrawal due to tremors

Early conversations, open the door to better management, specific treatment plans, and the support that can profoundly change your quality of life.

By bringing awareness to these tremors, we lessen stigma, validate individual experiences, and encourage earlier intervention. We begin to understand that Parkinson's is not just about movement, rather- life itself. Through that understanding, we begin to see not just the tremor. but the person living bravely behind it. ■

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