

Parkinson

PULSE

Connecting people living with Parkinson disease in Alberta



SLEEP ISSUES



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April is



PARKINSON AWARENESS MONTH

Get Involved at www.parkinsonassociation.ca



6 A Restful Night's Sleep



14 REM Sleep Behavior Disorder



16 Sleep Issues & Care Partners

Spring 2024

IN THIS ISSUE...

Features

- 4** **Cover Story**
Sleep Issues
- 6** **A Restful Night's Sleep**
Navigating Sleep Hygiene for
Individuals with Parkinson Disease
- 8** **Nocturia**
A Small Disturbance That Has a
Big Effect on How Rested You Feel
- 12** **Insomnia**
Are You Getting Enough Sleep?
- 14** **REM Sleep Behavior Disorder**
Are You Acting Out Your Dreams?
- 16** **Sleep Issues & Care Partners**
Sleep Is Essential for Everyone,
Including Care Partners
- 19** **Excessive Daytime Sleepiness**
Controlling When and
How Much You Sleep

Every Issue

- 3** **MESSAGE FROM OUR
EXECUTIVE DIRECTOR**
- 11** **PROGRAM NEWS & UPDATES**



Parkinson Association of Alberta is the source for support, education and inspiration for people impacted by Parkinson disease and Parkinson's Plus Syndromes, and engagement in important quality of life research with an emphasis on Alberta.



Articles and information contained in the Parkinson Pulse are provided solely for the reader's interest. Articles do not necessarily reflect the views of Parkinson Association of Alberta and are NOT intended as medical advice. Please consult your doctor or neurologist in all matters relating to health concerns or medication.

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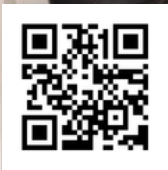


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Message from our Executive Director

Dear friends,

I wanted to take a moment to express my gratitude for your continued support and dedication to the mission of Parkinson Association of Alberta. Our team is continuing to evolve as is the way we connect with individuals and groups across the province and beyond. Our goal is always to respond to the changing needs of those who come to us and it's only with your feedback and participation that we are able to do so. Your involvement and enthusiasm are the cornerstone of our success, and I am continually inspired by the strength and resilience of our community.

April marks Parkinson Awareness Month, a time dedicated to raising awareness about Parkinson's disease and its impact on individuals, families, and communities. Throughout the month, we will be sharing resources, hosting events, and engaging in advocacy efforts to increase understanding and support for those affected by Parkinson disease. More information can be found in the following pages and on our website.

I am also pleased to announce that our annual general meeting will be held on Saturday, May 25th in Edmonton and via Zoom. This is a wonderful opportunity for us to come together as a community, reflect on our accomplishments over the past year, and

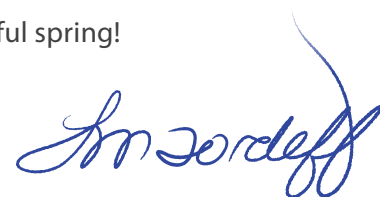
chart the course for the year ahead. More information about the AGM will be provided via our newsletter and on our website, so please stay tuned for updates.

This edition of Pulse focuses on sleep. In recent years, we've started to hear more about good sleep hygiene, which is really just the habits and practices that are conducive to sleeping well on a regular basis. Sleep plays a crucial role in maintaining physical and mental health for everyone, but it is essential for managing the symptoms of Parkinson's. Parkinson disease comes with its own set of sleep challenges over and above those more broadly experiences. We hope the information put together by our amazing Client Services team will provide valuable insights and practical tips for improving your sleep hygiene and managing Parkinson's related sleep issues.

Please do not hesitate to connect with me or members of our team with any comments or questions you may have. I look forward to hearing from you.

All our best for a peaceful spring!

Lana



Saturday
May 25 @ 11am

**SAVE
the
DATE**



 **Parkinson 2024**
Association of Alberta

**ANNUAL
GENERAL
MEETING**

Be sure to purchase your membership by
April 26 in order to vote

SLEEP ISSUES



*“Sleep is an investment
in the energy you need to
be effective tomorrow.”*

- Tom Roth

Written By: **Brandi La Bonte**

Sleep is a vital part of living well. In fact, the way we feel while we are awake depends, in part, on how we slept. You see, during sleep, our bodies are working to support healthy brain function and maintain our physical and mental health (including our immune system). Not getting enough sleep over time can increase our risk of health problems like heart disease, high blood pressure, and stroke. Sleep helps with learning and the formation of long-term memories. A lack of sleep can lead to problems with focus, clarity

of thought, reaction times, and our ability to learn. Inadequate sleep can also have a significant impact on our mood causing both mood swings and irritability.

There are two phases of sleep that we cycle through while we sleep – rapid eye movement (REM) and non-REM sleep. Assuming a full eight hours of sleep, most people go through four-five cycles a night with each cycle lasting 90-120 minutes. For some getting that coveted 7-9 hours of sleep a night is easy, for others it's elusive and stressful.

For those without Parkinson's stress, nighttime urination, physical health conditions, or concern about our loved ones can lead to poor sleep. For people with Parkinson's, unfortunately the list of reasons associated with poor sleep can be longer. People living with Parkinson's often experience issues with sleep; some are associated with the disease itself, while others may be linked to the medications used to treat symptoms. Issues with sleep can include the following:

- » Trouble falling asleep and/or trouble staying asleep
- » Sleepiness during the day including falling asleep suddenly ("sleep attacks")
- » Vivid dreams or nightmares; acting out dreams
- » Talking, yelling, or kicking while sleeping
- » Frequent waking up to go to the bathroom
- » Jerking, cramping, or moving of the legs
- » Trouble turning or shifting in bed

Throughout this issue we cover a variety of sleep issues that can affect people with Parkinson disease. If you are having trouble with sleep, make sure your doctor/healthcare team is aware of the specific problems you are having.

- » Sleep difficulties may be related to the medications you are taking for Parkinson's. Your doctor may be able to change the dose, type of medication or timing of medication to help your sleep.
- » You may learn tips to better cope with these problems from your healthcare team.
- » If you have a bed partner, it is important to include them in this conversation as their sleep may be affected by your sleep challenges.



*"Sleep is the single most effective thing we can do to reset our brain and body health each day."
- Matthew Walker*





A Restful Night's Sleep

Navigating Sleep Hygiene for Individuals with Parkinson Disease

Written By: *Brienne Leclaire*

Living with Parkinson Disease comes with many challenges, one often underestimated side is the impact on sleep. Sleep disturbances are prevalent among individuals with Parkinson's, with issues such as insomnia, restless legs syndrome, and frequent waking during the night. This leads to disruptions in sleep patterns, fatigue and a diminished quality of life.

Improving one's sleep hygiene can help improve sleep quality and get a better night's sleep. Sleep hygiene refers to a set of practices and habits that promote healthy and restful sleep. It encompasses everything from the bedtime routines to the sleep environment and even dietary choices. By cultivating good sleep hygiene, individuals can enhance the quantity and quality of their sleep, leading to improved physical and mental health.



Sleep schedule:

One of the fundamental pillars of sleep hygiene is establishing a regular sleep schedule. Our bodies thrive on routine, and a consistent bedtime and wake-up time help regulate our internal circadian rhythm. Aim for seven to nine hours of sleep each night, aligning with your individual needs.

Bedtime routine:

Creating a calming bedtime routine, signals to your body that it's time to wind down. This might involve activities such as reading a book, taking a warm bath, or practicing relaxation techniques like deep breathing. By dedicating time to unwind before bed, you pave the way for a smoother transition into restful sleep.

Screen time:

Screen time before bed can impact the quality of our sleep and our ability to fall asleep before bed. Light from screens can disrupt our sleep cycle. Particularly screens like TV, tablets and cell phones that emit blue light. Limiting screen time before bed, turning off any screens an hour or more before bed and reducing the blue light exposure can help improve our sleep.

Sleep space:

Your bedroom plays a pivotal role in the quality of your sleep. Ensure the room is a comfortable temperature, dark, and quiet. Invest in a comfortable mattress and pillows that provide proper support. Consider blackout curtains to block out external light and minimize electronic devices in the bedroom to reduce disruptions.

Dietary changes:

What you consume can impact your sleep. Limit caffeine, alcohol and nicotine intake, especially in the hours leading up to bedtime. Additionally, be mindful of your evening meals—opt for light, easily digestible snacks and avoid heavy, rich foods that may cause discomfort during sleep. If you find you need to get up frequently to use the bathroom overnight reducing fluid intake in the evening can help reduce disruptions in your sleep for having to use the bathroom.

Exercise:

Regular exercise is an effective ally in the quest for better sleep. Exercise can help burn off extra energy, improve our physical and mental health and help us relax; but be strategic about timing. Aim to complete your workout several hours before bedtime to allow your body to wind down naturally.



Stress and anxiety:

Stress and anxiety can make it difficult to fall asleep and detrimental to quality sleep. Incorporate stress reduction techniques into your daily routine, such as meditation, deep breathing, yoga, or mindfulness exercises. These practices can help quiet the mind and promote relaxation.

While Parkinson Disease may present challenges to a good night's sleep, incorporating these sleep hygiene practices can significantly improve sleep quality and overall well-being. Always consult with your healthcare team for personalized advice and adjustments to your sleep routine. A good night's sleep is not just a luxury; it's an integral part of the holistic approach to managing Parkinson Disease.



Nocturia

A Small Disturbance That Has a Big Effect on How Rested You Feel

Written By: **Brett Leclaire**

We have all had those moments where you are suddenly awoken from a wonderful sleep with the abrupt urge to use the washroom late at night to pee. A small disturbance that has a big impact on how rested you feel the following morning. If these sudden and frequent urges to use the washroom overnight are something you are suffering from then you might be experiencing a sleep condition called nocturia.

What is Nocturia?

Nocturia is defined as the consistent occurrence of waking at night one or more times to empty your bladder. While occasional night-time urination is considered normal; persistent and disruptive nocturia typically involves two or more episodes each night. This condition can affect individuals of all ages but becomes more prevalent as one ages. Sleep is a fundamental part of our overall health so when we are disturbed with a need to get up and pee consistently, it will likely have a negative impact in other parts of our daily lives as well.

If you suspect there might be a link between nocturia and Parkinson disease, you are correct.

Parkinson disease affects the coordination of muscles, including those involved in urination and the bladder. People with Parkinson's can experience difficulty initiating urination or fully emptying their bladder when using the washroom. This incomplete emptying can result in the need to urinate more frequently, especially during the night when you lay down. Nocturia in Parkinson disease can be complex. Other sleep issues, changes in mobility and the tremors associated with Parkinson's can lead to frequently awakening during the night, and the combination of disrupted sleep and bladder dysfunction largely contributes to the likelihood of experiencing Nocturia.

What are the causes of Nocturia?

Aging

As we age many parts of our bodies change, we also see that changes in bladder function are common across the process of ageing. Over the years one's bladder may lose its capacity to hold urine, and the ability to concentrate urine diminishes, leading to increased nighttime urination. It is very common for adults to experience it in their lifetime with 30% of those 20-40, 50% of individuals over 50 and 70% of people aged 70 and over.



Overactive Bladder

Overactive bladder is characterized by sudden, involuntary contractions of the bladder muscles, causing a strong urge to urinate. Overactive bladder can contribute to nocturia as these contractions typically become more active during the night. The use of botulinum toxin (Botox) can be discussed with your healthcare team, as it can be helpful in reducing frequency and urgency due to an overactive bladder.

Motor Symptoms

The motor symptoms of Parkinson's such as tremors, stiffness, and difficulty in initiating and controlling movements can affect the bladder muscles as well. These motor symptoms can affect the coordination of muscles involved in urination, leading to difficulties in fully emptying the bladder. Essentially, this can mean that you retain more in your bladder increasing the likelihood that you need to get up in the middle of the night.

Urinary Tract Infections (UTIs)

Infections of the urinary system can lead to irritation and inflammation, causing an increased sense of urgency and frequency, particularly during the night. It's like your body is saying "Hey, let's get rid of these germs right now!" Also, these infections can make things a bit swollen and irritated, causing you to feel the need to urinate more often.

Medications

Certain medications, such as blood pressure pills, Levodopa, and sedatives can influence bladder function and/or increase urine production, contributing to nocturia.

- » Levodopa, one of the most common medications for Parkinson disease, has been known to increase urine production and urgency in some people.
- » Sedative medications can be used to induce relaxation and improve sleep for those that are experiencing sleep difficulties. However, these types of medications can also relax the urethra and bladder muscles resulting in feeling an increased need to urinate.

Habits

Our habits prior to bed can influence our probability of experiencing nocturia when in combination with these above-mentioned factors. A final big glass of water or milk just before bed will fill our bladder up and increase the chance that we need to get up to urinate in the middle of the night. Other habits to watch out for include eating a salt heavy diet, which causes your body to retain more fluids, and those late afternoon teas or coffees containing caffeine.



Effects of Nocturia



Disrupted Sleep

Nocturia disrupts the normal sleep cycle which prevents you from reaching deep, restorative sleep. This can result in daytime fatigue, diminished cognitive function, and irritability.

Impact on Quality of Life

The constant need to wake up and navigate nighttime trips to the bathroom can affect daily activities, limit our capacity for social engagements, and impact overall quality of life by increasing daytime fatigue. Think how much we miss on those days we are tired and grumpy; those days are always less vibrant for us and have a big impact on our overall feeling of wellbeing.

Increased Fall Risk

Multiple nighttime awakenings increase the risk of falls, particularly as mobility changes from both ageing

and the progression of Parkinson's. The path to the washroom may not be challenging during the day, but with the evening darkness and being tired, we can forget how many obstacles, like tables, chairs, or rugs, can be in the way and can increase the risk of falling. A relatively easy solution for this can be managed by the addition of a nightlight to guide your path to the washroom.

Emotional Consequences

Nocturia and the effects of this sleep condition, specifically lack of restful sleep, can contribute to increased levels stress and anxiety. These increased levels can lead to emotional distress over time, difficulty regulating emotions, and impacts to resiliency when facing life's challenges. It is important to seek support when navigating these difficult emotions and consult your healthcare team for management techniques for nocturia.



The good news is there are some things you can do to help manage nocturia and get a better night's sleep. First, try limiting how much you drink in the evening to lessen the chance of waking up often at night to use the bathroom. Second, if possible, try using the bathroom regularly throughout the day to avoid a full bladder in the evening. Third, avoid drinking alcohol or caffeinated beverages (coffee, tea, sodas) especially in the evening. Finally, it is important to keep up with a healthy lifestyle, like exercising, eating well, and managing stress, which can all help improve sleep.

It is important to regularly talk to your healthcare team about changes in medications to determine if they may be contributing to the issue and find the best ways to manage and improve your quality of sleep and overall health.

PROGRAM NEWS & UPDATES

Spring Socials!

For Parkinson Awareness Month, we have over 20 exciting socials happening across the province between March and April. Socials are a fun and relaxed way to connect, chat and enjoy some tasty snacks. Check out parkinsonassociation.ca for a location near you and call 1-800-561-1911 to register

PWP (People with Perseverance) Exercise Social Chat

This is a group for people who enjoy exercising and like to live an active and engaged lifestyle. Connect with others through this group to share ideas, stories, goals, and keep each other motivated! To join this drop-in group, call us at 1-800-561-1911 for the zoom link information.

Education 101 Series

PAA has taken the most asked about topics and questions and turned them into an Education 101 Series. This is a great way to provide quality information so that you and/or your loved ones are able to make the best decision possible. There are several offered throughout the year and at various times to allow as many people to attend as possible. Call 1-800-561-1911 for more information or to register.

WHAT'S NEW?



Important Dates to Remember

April 11

Stand Up to Parkinson's events (Cgy & Edm)

April 26

Last day to renew memberships for a chance to vote at our AGM

May 25

Annual General Meeting (in-person and virtual)

June 15

Cars for a Cause (Edm)

All PAA Offices closed on the following dates:

March 29

Good Friday

April 1

Easter Monday

May 20

Victoria Day

July 1

Canada Day



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INSOMNIA

Are You Getting Enough Sleep?

Written By: *Emma Torneiro*

Did you know we spend roughly 1/3 of our lives sleeping? However, this fact is true only if we're sleeping eight hours per night, which is, unfortunately, uncommon for many individuals impacted by Parkinson disease due to the variety of sleep issues associated with the disease. One of the most reported sleep disorders is insomnia. The prevalence of insomnia in those diagnosed with Parkinson's is higher (affecting up to 80% of people with Parkinson's) than the general public, with occurrence increasing as the disease progresses.

Insomnia defines a sleep disorder characterized by the inability to sleep due to one of three issues:

- » difficulties falling asleep,
- » frequent waking leading to fragmented sleep, or
- » waking too early leading to insufficient amounts of sleep needed for daily functioning.

The type of sleep disruption categorizes the three (3) levels of insomnia:

- » **Initial** or **Sleep Onset** refers to trouble falling asleep,
- » **Middle** or **Maintenance** refers to frequent waking with the ability to return to sleep, and
- » **Late** or **Early Waking** refers to inability to fall back asleep after waking early.

For those diagnosed with Parkinson's, the causes of insomnia can stem from the chemical changes occurring within the brain, the duration and progression of the disease, gender (female), the prevalence of depression or anxiety, side effects of medications (amantadine and MAO-B inhibitors like Selegiline or Rasagiline), the inability to sleep due to motor symptoms (rigidity or dystonia) or autonomic dysfunction symptoms (ex. nocturia), inability to sleep due to vivid dreaming or REM Sleep Behavior Disorder, or other undiagnosed sleep disorders (ex. sleep apnea).



A lack of sleep from insomnia can increase fatigue levels throughout the day leading to feeling exhausted, sleepy, or unwell. Additionally, insomnia can cause delayed cognitive processing and responses, difficulties with memory, and significant mood disruptions thereby impacting day-to-day functioning. When thinking about the effects of insomnia, one may notice the overlap of symptoms with Parkinson disease progression. For example, Parkinson's on its own can cause fatigue and changes to cognitive functioning; the effects of insomnia can create added difficulties, so it is important to try to manage these symptoms to ensure consistent good rest to help you successfully navigate the disease.

Since we know how important the connection between good sleep and daily functioning is, you might be wondering how insomnia is diagnosed and what treatment options are available. A diagnosis

of insomnia is based on self-reported symptoms to your healthcare team and can include sleep studies to rule out additional sleep disorders. The diagnosing characteristics of insomnia include sleep disruptions occurring regardless of external circumstances, such as lifestyle changes or events causing stress, and a frequency that is consistently 3x per week for three (3) months.

Treating insomnia can take time and it is important to consult with your healthcare team regarding any medication questions or changes for management of Parkinson's and insomnia. One treatment option for managing insomnia would be requesting an assessment with your neurologist or healthcare team to discuss your Parkinson's medications – considering the timing, dosage, or possible removal of medications causing insomnia as a side effect. The adjustment of medication schedules or types of medications (ex. long acting or controlled release) could help with the management of motor symptoms overnight, which would result in better quantity and quality of sleep. If your healthcare team deems applicable, they may recommend natural sleeping remedies (ex. Melatonin) or prescribe sleep aids to use with caution to manage the symptoms of insomnia. It is also important to consult your healthcare team for medical or therapeutic management of mood disorders, specifically depression and anxiety, which can increase your risk factor for insomnia.

Additionally, your healthcare team could request a sleep study to understand sleeping patterns and determine if other sleep disorders exist that could be treated. Finally, the treatment of insomnia can include lifestyle changes to improve quality and quantity of sleep, including reducing naps throughout the day or limiting naps to 45 minutes or less in the early afternoon, creating a sleep hygiene routine to follow, and getting out of bed when you're unable to sleep and returning when you're feeling tired again.

Finally, if this article made you sleepy (*I won't be offended if it did*), read this every night before bed!

REM Sleep Behavior Disorder

Are You Acting Out Your Dreams?

Written By: *Brienne Leclaire*



REM Sleep Behavior Disorder is a unique and complex condition that is considered a parasomnia. A parasomnia is a grouping of sleep disorders that occur in the state between sleeping and wakefulness and involve unusual and undesirable physical symptoms.

These symptoms can include things like abnormal movements, talking, expressing emotions, or a host of other unusual things. While not necessarily concerning for some who experience parasomnia; it can become problematic when a person with the condition unknowingly causes injury to themselves or others. In fact, parasomnia is often more concerning for the non-affected person who is witnessing the behavior.

There are two main types/stages of sleep – rapid eye movement (REM) and non-rapid eye movement (non-REM); and parasomnias are grouped by the stage within which they occur. REM sleep is the part of the sleep cycle when one's more vivid dreaming occurs, your eyes move rapidly under your eyelids, and heart rate, blood pressure, and breathing increases. This is also the stage of sleep where REM sleep behavior disorder (RSBD) occurs.

What is REM sleep behavior disorder?

REM sleep behavior disorder is characterized by the loss of normal muscle paralysis during REM (rapid eye movement) sleep, leading to the acting out (physical and vocalization) of dreams/nightmares during sleep. Normally, during REM sleep, you do not move or talk; your brain sends signals to inhibit these particular activities. A temporary muscle paralysis - called atonia – while our brains are wide awake with activity (dreams, emotional processing, etc). For those with RSBD this temporary paralysis is impaired, leaving them to act out their vivid, action-packed, and/or violent dreams/nightmares. This can range from simple limb twitches and whispers to hand gestures and talking to more violent grabbing/kicking and shouting/swearing. Individuals with REM Sleep Behavior Disorder may even jump up or fall out of bed. These behaviors can have a significant impact on sleep and pose a serious risk – not only to oneself but to anyone they share a bed with. In fact, up to 90 percent of spouses of those with REM sleep disorder report having sleep issues and over 60 percent have experienced a physical injury¹.

It is important to note that individuals are NOT aware of these behaviors during the episode. They often find out when told by a sleep partner/housemate or when they wake up with an injury or injuries. Individuals experiencing an RSBD episode can typically

be woken up fairly easily and are alert, coherent and able to recall the content of the dream/nightmare.

The frequency of RSD episodes can vary – a few times per year or every night, once per night or multiple times; and, unfortunately, symptoms typically worsen over time.

How does Parkinson's fit in?

While REM Sleep Behavior Disorder is relatively rare; it is more common in men and adults over 50 – which is where one of the correlations between RSD and Parkinson's can be noted. Not only is the biggest risk factor for Parkinson's aging; research has also shown RSD to be "disproportionately prevalent" in Parkinson's, with estimates ranging from 33-47%². Another correlation of note is the research that suggests individuals with RSD are at an increased risk of developing Parkinson's or other neurological conditions impacting the alpha-synuclein protein in the brain (ie: MSA, DLB); with many Parkinson's patients experiencing RSD symptoms prior to their Parkinson's diagnosis

The exact mechanisms underlying the relationship between RSD and Parkinson's are not fully understood, but it is believed that both conditions share common systemic processes. The abnormal accumulation of alpha-synuclein in specific brain regions, including the brainstem, is a hallmark feature of both RSD and Parkinson disease.

How is RSD diagnosed?

Diagnosing RSD in people with Parkinson's involves a thorough clinical evaluation, including a detailed sleep history, medical history and may involve a sleep study that monitors brain activity, eye movement, muscle activity, heart rate, and other parameters during sleep. This evaluation aids in the identification of abnormal behaviors during REM sleep.

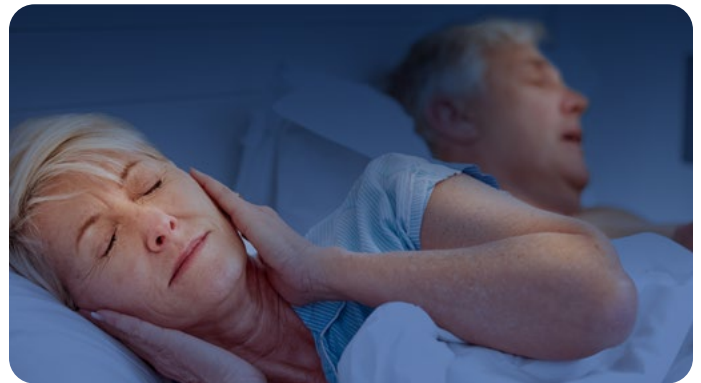
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¹⁾ Lam, S. P., Wong, C. C., Li, S. X., Zhang, J. H., Chan, J. W., Zhou, J. Y., Liu, Y. P., Yu, M. W., & Wing, Y. K. (2016). Caring burden of REM sleep behavior disorder – spouses' health and marital relationship. *Sleep medicine*, 24, 40–43.

²⁾ Mahmood, Z., Van Patten, R., 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. *J Int Neuropsychol Soc*. 2020 Oct; 26(9): 894–905.

Managing REM Sleep Behaviour Disorder

Treatment strategies often involve a multidisciplinary approach, including neurologists, sleep specialists, and sometimes psychiatrists. Working to remove dream/nightmare triggers is the first step. Reducing agitating and stimulating things prior to sleep is a great place to start. News, action shows, caffeine and alcohol intake can increase symptoms of RSD. Your doctor might recommend Melatonin to help aid with sleep and reduce symptoms. Medications such as clonazepam, a benzodiazepine, are commonly prescribed to suppress the motor symptoms associated with REM Sleep Behaviour Disorder. However, the potential side effects and interactions with Parkinson's medications must be carefully considered.



REM sleep behavior disorder in Parkinson Disease represents an intriguing intersection between neurology and sleep medicine. Recognizing and addressing REM Sleep Behaviour Disorder in Parkinson's patients is crucial for improving the overall quality of life for individuals living with these conditions. Ongoing research into correlations between REM sleep behaviour Disorder and Parkinson disease may provide valuable insights into the underlying causes and potential interventions for both disorders.

Sleep Issues & Care Partners

Sleep Is Essential for
Everyone, Including
Care Partners

Written By:

Brandi La Bonte & Charlene Heavener



Caring for another human being is one of the most incredible acts of love there is. As we get older and/or a loved one is diagnosed with Parkinson's the level of care required can change. With Parkinson's the need for care typically changes gradually, over time. Sleep (or lack thereof) is one of the ongoing changes that can wreak havoc on both the person with Parkinson's AND you as a loved one. Without adequate sleep, you may find yourself more irritable, physically weaker, less patient, lacking focus, and generally exhausted.

You may find yourself struggling to manage expectations (of yourself, your loved one, and others). You may find yourself "nagging" or snapping at your loved one or others more, leading to increased feelings of guilt. As a care partner you may find yourself often minimizing your own sleep issues and feeling that your sleep is less important than what is happening with your loved one. You may think that you can "get by" on limited sleep and "catch up" on that missing sleep later.

Research indicates that "up to 76% of caregivers report poor sleep quality, and the proportion is considerably higher for female caregivers compared to male caregivers."¹ This number increases exponentially (up to 92%) when the care partner is providing advanced care or the person, they are providing care for has significant cognitive issues. In general, poor sleep quality in care partners can be attributed to two causalities: 1) those associated directly with the act of providing care such as increased role overload, lack of support, stress, physical and mental challenges in

one's own day-to-day. And 2) those associated directly with the actions of their loved one such as a loved one's insomnia, REM Sleep Behavior disorder, nighttime wandering, frequent trips to the bathroom, etc.

Let's address those sleep issues associated directly with the act of providing care first. Sleep is essential for everyone, including care partners; but between regular life and caregiving responsibilities getting enough quality sleep can be a big challenge.

- » **Increased responsibilities** – You may find yourself taking on household responsibilities that were once your loved one's domain when they are no longer able to manage such tasks safely or effectively. Things like driving, cooking, yard work, banking, laundry, etc. may not seem like huge, earth-shattering tasks, but the little things add up and can make it difficult to feel like you can get it all done in a day. You may find yourself getting up earlier or staying up later to get your growing to do list completed.
- » **Change in routine/role** – As the need to provide care for your loved one increases; you may find your own health and self-care routine gets eroded – after all there are only so many hours in a day. You may put off your own medical appointments and have less time for fresh air, exercise, relaxation, social connections which can all reduce stress and promote sleep. You may also find yourself consuming more caffeine to help fight fatigue and feeling "run down" which will hinder sleep.
- » **Stress/Worry** – You may find it challenging to quiet your mind – especially at night. Thinking about concerns, challenges, to do lists, or even all the "what ifs" can make it difficult to relax and fall asleep or may even wake you up in the middle of the night leading to insufficient and poor-quality sleep.
- » **Lack of support** – You may not have family available to help you and/or programs and services that help provide respite might be limited (or non-existent). And, even if either is available to you, you may find it hard to ask for/accept help or trust someone else to provide care and support for your loved one. You may also experience frustration/guilt if your loved one is struggling/not willing to accept outside help.

As you have read (or will read) throughout this issue, there are a variety of sleep-related issues in Parkinson disease. These sleep-related issues are attributed to the second causality of poor sleep for you as a care partner wherein your loved one's actions (as a result of Parkinson's and/or Parkinson-related issues) directly impact your sleep quality.

- » **Needs of your loved one** – As Parkinson's progresses and new challenges appear you will likely find yourself needing to help your loved one more frequently during the nighttime. Medication management, help to the washroom or even with repositioning in bed. Additionally, symptoms like pain, restless legs, or even anxiety can keep your loved one from sleeping, which can impact your ability to sleep as well.
- » **Sleep-Issues in Parkinson's** – From insomnia to nighttime wandering to REM Sleep Behavior Disorder there are a host of sleep-issues in Parkinson's that result in your loved one doing things (consciously or unconsciously) that impact your ability to get a good night's sleep. It could be the sound of the tv turning on at 1:30AM, or the rattling of dishes in the kitchen at midnight by your loved one who either has insomnia or can't sleep because of the excessive daytime sleepiness they've been experiencing. Maybe you've been jolted awake by your loved one yelling or even kicking or hitting you – your heart and mind racing while you scramble to figure out what the hell is going on. Or you've woken up one too many times with that cold feeling knowing something is off and finding your loved one by the open front door putting their slippers on to go outside at 3AM.

Burnout, stress, exhaustion, frustration, guilt, fear for your loved one's safety, and fear for your own safety – none of these things are conducive to getting a good night's sleep. You may find yourself asking the following questions: Do I stay up with them? Or try to settle them back to sleep? Do I force myself to try to go back to bed and then try to sleep?





What is a care partner to do?

When your loved one has Parkinson's your advocacy role is ongoing; you cannot, however, forget to advocate for your own health and wellness too. Be sure you are bringing up sleep issues with both YOUR treating physician and your loved one's healthcare team. Having honest conversations with not only your loved one (if they are able) but with yourself can help you figure out next steps. If your loved one is cognitively unable to have this conversation or you feel like you need additional support, you may also want to consider including adult children or support network in the conversation.

Since these issues can be as varied as the people impacted by them, there is no one size fits all solution we can share in one magazine. Next steps can vary, but may include:

- » practical solutions like satin sheets/pjs for ease of movement in bed, a clear path and lighted access to the washroom, limiting liquids, and/or adjusting daytime naps.
- » purchasing mobility supplies for your loved one's safety and independence (i.e.: a bed rail, non-slip carpets, stability bars/poles).
- » consider accessing a day program if possible.
- » bringing in help (home care, family support, cleaning service, meals on wheels, etc.).
- » considering new sleeping arrangements (separate rooms); and
- » if your safety and/or your loved one's safety it may be time to consider a safer, alternate living arrangement such as a lodge or care facility.

Issues affecting sleep typically happen gradually over time; thankfully this means that we have an opportunity to seek support and create an action plan to improve sleep quality. We acknowledge that it can be hard to ask for help and advice; however, seeking support can open the door to solutions that help to promote your health and wellness. Remember, we are here for YOU as well!

Reference

¹ *How Adult Caregiving Impacts Sleep: a Systemic Review.* E. Byun, A. Lerdal, C. Gay, and K. Lee. *Curr Sleep Med Rep.* 2016; 2(4): 191-205. doi: 10.1007/s40675-016-0058-8

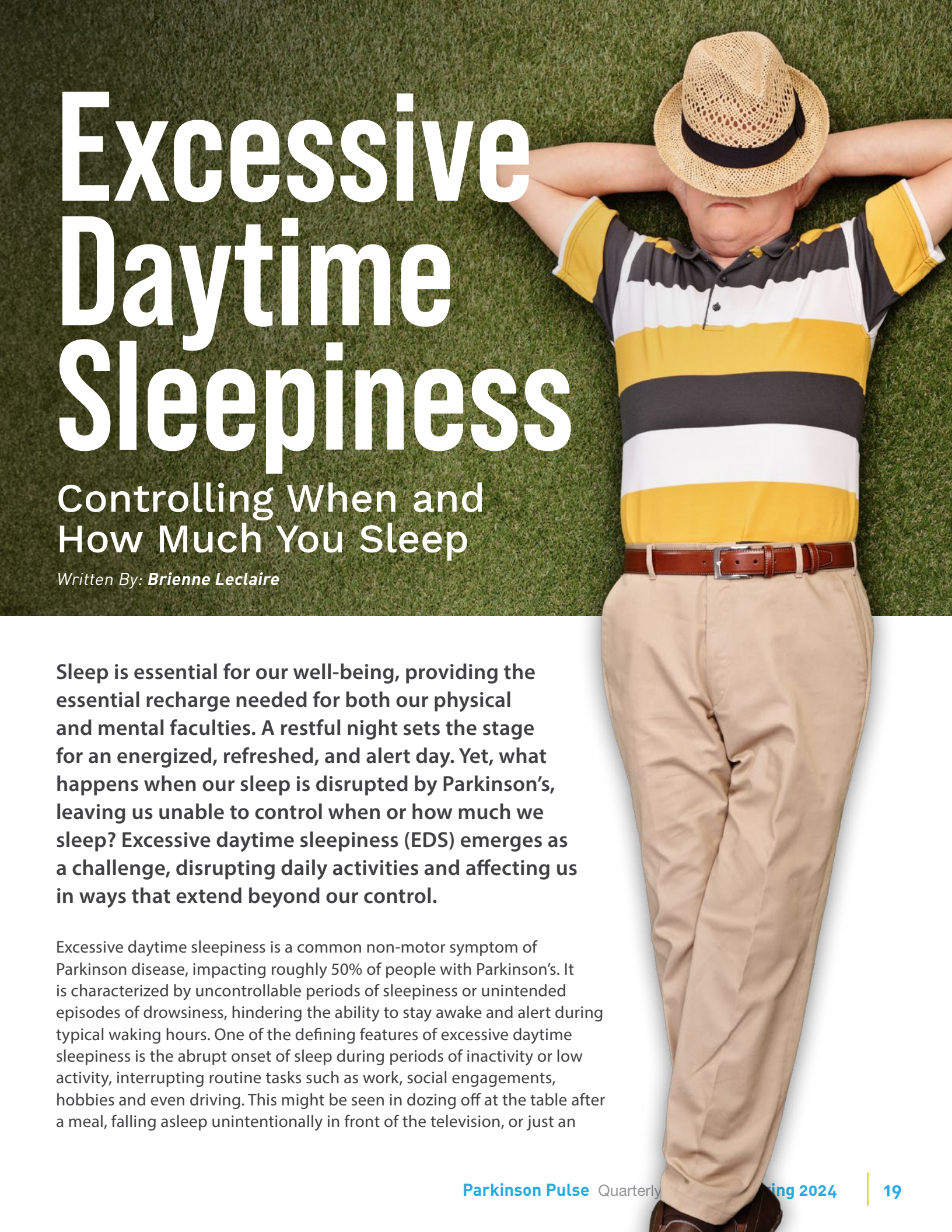
Excessive Daytime Sleepiness

Controlling When and How Much You Sleep

Written By: *Brienne Leclair*

Sleep is essential for our well-being, providing the essential recharge needed for both our physical and mental faculties. A restful night sets the stage for an energized, refreshed, and alert day. Yet, what happens when our sleep is disrupted by Parkinson's, leaving us unable to control when or how much we sleep? Excessive daytime sleepiness (EDS) emerges as a challenge, disrupting daily activities and affecting us in ways that extend beyond our control.

Excessive daytime sleepiness is a common non-motor symptom of Parkinson disease, impacting roughly 50% of people with Parkinson's. It is characterized by uncontrollable periods of sleepiness or unintended episodes of drowsiness, hindering the ability to stay awake and alert during typical waking hours. One of the defining features of excessive daytime sleepiness is the abrupt onset of sleep during periods of inactivity or low activity, interrupting routine tasks such as work, social engagements, hobbies and even driving. This might be seen in dozing off at the table after a meal, falling asleep unintentionally in front of the television, or just an





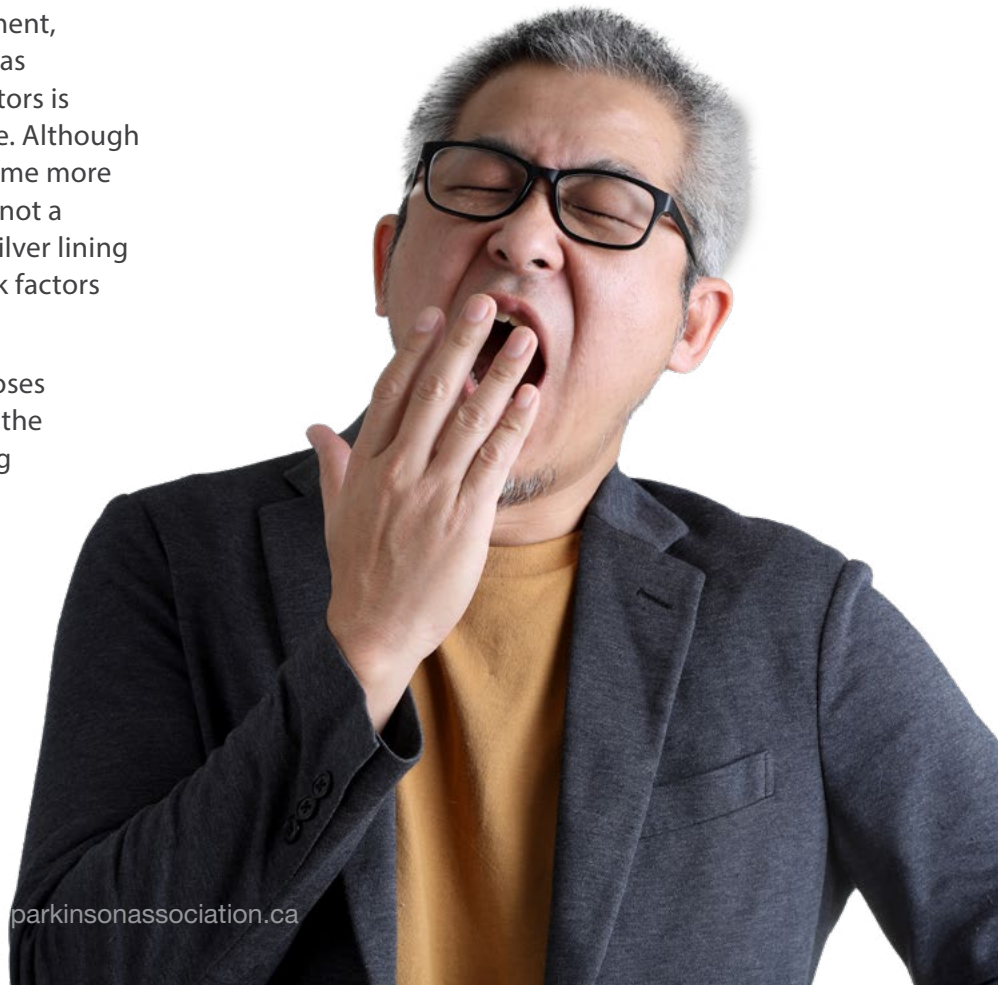
overall feeling of sleepiness at times of the day that is not a typical time for sleep. This can place a substantial burden on those impacted, diminishing quality of life.

Several sleep factors can contribute to the development of excessive daytime sleepiness in Parkinson's, including lack of sleep, poor quality of sleep, and sleep apnea. Other risk factors include age, certain medications, disease advancement, and cognitive decline have been identified as contributing factors. Recognizing these factors is important for preserving one's quality of life. Although excessive daytime sleepiness tends to become more pronounced as Parkinson's progresses, it is not a constant rather fluctuating over time. The silver lining lies in the fact that understanding these risk factors can help with prevention and treatments.

Living with excessive daytime sleepiness poses challenges, but dismissing its impact is not the solution. If you or a loved one are struggling with the challenges of excessive daytime sleepiness, your doctor is an important ally. Your doctor may adjust medication regimens to increase dopamine and or prescribe medications to enhance sleep quality and reduce daytime sleepiness. Furthermore, lifestyle adjustments like eating healthy and avoiding alcohol can help reduce symptoms of excessive daytime sleepiness. While some find

caffeine helpful in reducing sleepiness during the day; this needs to be weighed against the possibility of caffeine impacting sleep at night and impact on Parkinson's symptoms. Exercise is an important part of combating excessive daytime sleepiness. Regular exercise can help reduce sleepiness and improve alertness. Lastly, adhering to a consistent sleep schedule can help reduce daytime sleepiness and improve sleep quality. Incorporating strategic naps can contribute to improved wakefulness. These are naps that are not too close to regular bedtime and are short in duration about 15-20 minutes. Longer naps and naps closer to one's typical bedtime can further interrupt the sleep schedule.

Excessive daytime sleepiness can impact the lives of those with Parkinson's, but by understanding its impact, identifying risk factors, and seeking effective solutions can bring light to the darkness. By acknowledging the challenges posed by excessive daytime sleepiness, we pave the way for improved well-being, safety, and an empowered approach to living with Parkinson's disease.



PARKINSON AWARENESS MONTH EVENTS

APRIL

2024

LUNCH & LEARNS

Register for our free webinars and hear the latest news on the Parkinson's research taking place right here in Alberta!

**WEDNESDAY'S
NOON**

STAND UP TO PARKINSON'S EVENT

Celebrate Parkinson Awareness Day with us in Edmonton & Calgary with a fun pancake breakfast as we all complete 10,000 sit 'n stands together!

**APRIL
11**

LIGHT UP FOR PARKINSON'S

Join us across the province as we light up Alberta in Blue! All locations will be lit up on April 11, 2024 after sunset.

**APRIL
11**

SPRING SOCIALS

Let's get together for some great food and celebrate our community. Find a social near you to come out to!

**ALL
MONTH**

COMMUNITY FUNDRAISERS

Support PAA at one of our community partners as they fundraise for us all month long!

**ALL
MONTH**

JOIN US & GET INVOLVED!
WWW.PARKINSONASSOCIATION.CA

 **Parkinson**
Association of Alberta



CARS *for a* **CAUSE**

2024



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