

Parkinson PULSE

Connecting people living with Parkinson disease in Alberta



NON-MOTOR SYMPTOMS OF

Parkinson Disease

GREATEST HITS

VOLUME 2



CARS* for a *CAUSE

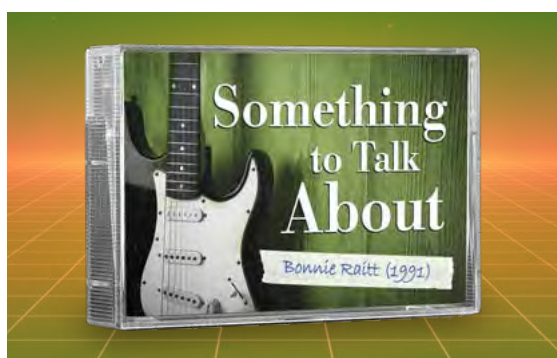
June 12 Edmonton June 19 Calgary



- ***Extensive Displays of Classic & Vintage Cars***
- ***Entertainment***
- ***Food and Beverage Stations***
- ***Door Prizes, Live Auction, Photo Opportunities & More!***



6 Sweat Issues in Parkinson's



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Spring 2022

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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.

We welcome your comments, suggestions and questions. Email us at communications@parkinsonassociation.ca; or call us toll-free at **1-800-561-1911**.

Parkinson Pulse is available (both past and present issues) as a free download via our website. Hard copies are available for mail out to current members who wish to receive one.

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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.

**JOIN OUR SAFE
AND CARING
COMMUNITY OF
SUPPORT**

BECOME A MEMBER





Dear friends,

While winter still has a stronghold on Alberta as I write this, my wish is that this edition of Pulse finds us all feeling the hopeful effects of spring.

As we start to come out of the two-year pandemic and its devastating impact on our world, we are faced with another horrific world event in the attacks on Ukraine. Nearly 10% of Alberta's population is of Ukrainian heritage and we have heard from so many of our friends in the community of their fear for their families and country of origin. We also have heard inspirational stories of support and bravery and we share the hope that peace is soon restored.

Inspiration is in good supply at Parkinson Association of Alberta, and we are grateful to our Parkinson's community for continuing to share your lives and experiences with us. April is Parkinson Awareness Month, and our focus is on research. Research informs so much of the work we do and the support we provide, and we are fortunate to have strong investment in PD research in Alberta. Each week, we will bring opportunities to learn about advances in and applications of research, as well as client experiences and an understanding

of the need for future investment. A full calendar of events can be found on **page 15**. Thank you to all our special guests for your involvement in Parkinson Awareness Month.

This edition of Pulse Magazine is a continuation of last summer's "Non-Motor Symptoms of Parkinson Disease, Greatest Hits Volume 1". Every person I know has Non-Motor Symptoms to varying degrees. Whether physical or emotional, we all manage things in our lives that are not evident to others. I find that fact quite comforting and hope you might see it the same way. When we recognize we are very often the same in our uniqueness, we can feel less isolated and open to human connection. For people living with or loving someone with Parkinson's, the more we understand about the un-seen, the better we can effectively communicate and manage the symptoms and their impact on daily life.

We hope you find something valuable in these pages and in our offerings during Parkinson Awareness Month. Happy Spring!

NON-MOTOR SYMPTOMS OF

Parkinson Disease



Written By: **Brandi La Bonte**

Greatest Hits Volume 2 is here! For those of you who may have missed out on Volume 1, a couple of notes before we continue. First, you can access Volume 1 on our website in the magazine section – it was released Summer 2021. Also, we recognize there is nothing “great” about non-motor symptoms. The “greatest hits” approach is simply a creative way to lead into these important topics and so we present this collection using musical references.

In music, greatest hits are a decent way for established performers to get their music to new or younger/older fans who are likely just learning about them. With our greatest hits, it is a way to introduce common issues in Parkinson disease to those individuals and families who may be recently diagnosed or who have not yet had access to the information. And, like music fans who simply want to listen to their favorite songs, it is our hope and intention that our current, long-standing clients also find value and insight into issues they may be experiencing at whatever stage of the Parkinson’s journey they may be in.

In this edition of Pulse we cover fatigue, sweating, vision and speech issues, and dystonia. One caveat, dystonia is kind of a weird one in that it is sort of a non-motor symptom but also considered a stand-alone disorder. We chose to include it either way because it does tend to affect so many people with Parkinson’s and we thought it deserved a mention in Volume 2. So, consider it that weird hit that some people aren’t too sure why it made the album.

We do know that it can be overwhelming sometimes to read about symptoms you may not be experiencing. A gentle reminder that not every symptom happens to everyone. The intent is to help people with Parkinson’s, Parkinson’s Plus Syndromes, and their loved ones understand what is happening, why it is happening and what can be done about it. Please reach out if you would like additional information, resources, or even practical tips on dealing with these or any other issues you may be experiencing. Have a great spring!



Written By: **Jordan Wiebe**

Have you ever felt like your body is just dragging on throughout the day, like you've just finished a big hike or ran a marathon, and your limbs just feel heavy? This feeling of heaviness deep inside your bones and muscles may make activities you like to do harder than they usually are. Perhaps you feel like no matter what you do, you cannot summon up the energy to do what you need or want to do in a day. The complex feelings of mentally or physically dragging throughout the day can be described as fatigue.

There are two ways of categorizing fatigue: peripheral or central. Peripheral fatigue is described as feeling a loss of muscle strength and is the type of fatigue experienced when working out. Muscle strength is often affected and seen during physical exercise; think about feeling like you've run a marathon and have just a little further to go. Central fatigue is considered subjective, and it is the person's perception of feeling tired, weak, or exhausted. This type of fatigue can involve either physical or mental components, sometimes both.

Fatigue is one of the most common Parkinson disease symptoms and can significantly hinder an individual's day-to-day activities. These disruptions in a person's ability to participate in activities they need or want to do can cause a significant impact on quality of life. Fatigue is present in 33-70% of people with Parkinson's, and

about 33% of people with Parkinson's consider it their most disabling symptom¹.

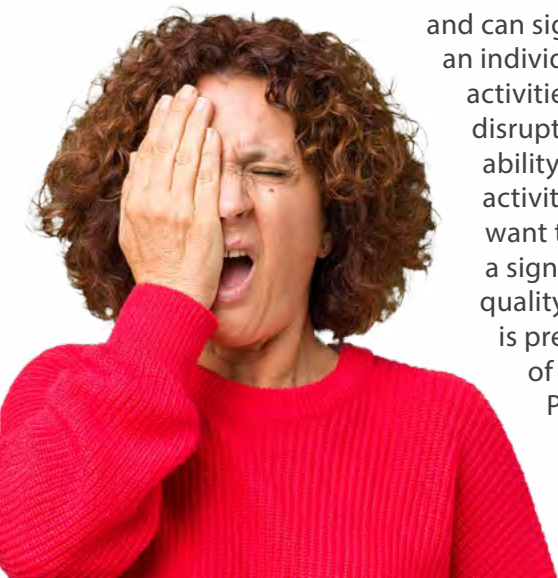
Fatigue is a little bit tricky to understand, and a clear definition does not exist. Without a clear definition and how different fatigue is for each person (just like Parkinson's), it can be extremely frustrating and challenging. To add to the complexity, fatigue may be a symptom all on its own, or it may be the result of another symptom like depression, anxiety, or apathy. If you are experiencing challenges or frustration with fatigue, it is important to chat with your doctor to help you figure out the cause of your fatigue.

It is commonly thought that fatigue is just another way of saying tired, but it is important to note that fatigue and sleepiness are not the same and should not be treated the same. An easy way to figure out if you are fatigued or sleepy is to look at how you feel after a nap or some rest. Sleepiness is often resolved with a nap; however, fatigue is not, and you may wake up after a nap feeling the same as you did before your nap. If you are experiencing fatigue, it is important to discuss your symptoms with your doctor. Unfortunately, there is no effective treatment for fatigue, but there are adjustments you could try making in your day-to-day life to help combat it.

Just like Parkinson's, your experience of fatigue may look very different from someone else's. Some helpful adjustments include exercising regularly (especially early in the day to kickstart your energy first thing), keeping a regular schedule, reducing stress, and most importantly, have fun!

References

¹ Nassif, D. V. & Pereira, J. S. Fatigue in Parkinson Disease: concepts and clinical approach. *Psychogeriatrics* 2018, 18: 143-150.





Written By: **Brienne Leclaire**

Affecting 70-80 % of people with Parkinson's, changes in sweating is a common non-motor symptom of Parkinson disease. Parkinson's can cause changes in the skin and autonomic nervous system resulting in changes in sweating and issues regulating body temperature. There are two major types of dysfunctions seen in sweating – hypohidrosis and hyperhidrosis; diminished and excessive sweating respectively.



Hypohidrosis

Hypohidrosis diminishes/reduces the body's ability to sweat to regulate body temperature and, increases sensitivity to temperature changes. Some describe hypohidrosis as the skin feeling dry across the whole body. It is also commonly described as feeling like being in a desert. Where it is hot but very dry. The cause can be related to anticholinergic or antiparkinsonian medications. Some also experience diminished sweating caused by the progression of

Parkinson disease itself.

Reduced sweating can impact a person's sleep, ability to partake in outdoor activities in the heat, difficulty transitioning between temperatures and dry or irritated skin. These all impact social, physical, and mental well being.

What can be done to manage hypohidrosis?

The condition can be managed through the use of medication if other non-drug remedies are ineffective. Outside of medication there are options that can help reduce the impact of diminished sweating.

These include, but are not limited to:

- » Avoiding extended periods of time in heat as much as possible can help reduce overheating and the risk of heatstroke.
 - This includes avoiding or limiting time in saunas, hot tubs, and direct sunlight on hot days.
- » Utilizing shade can help the body self regulate temperature better when outdoors for an extended period of time.
- » Wearing light clothing that is loose fitting along with hats and sunscreen.
 - This helps increase airflow, reduce sun exposure, and protect the skin from damage.
- » Avoid physical or strenuous exertion in the heat that would typically cause perspiration help reduce overheating.
- » Lastly keeping the skin moisturized with ointment or creams to reduce irritation from dry skin.

Hyperhidrosis

Excessive sweating (hyperhidrosis) is the more common sweating symptom associated with Parkinson disease. This particular type of sweating is not necessarily related to heat or exercise. Excessive sweating typically occurs in the upper body (underarm, palms of hands or face). It is described as sweating so much you become drenched in minutes or sweat dripping off your face and hands. The condition causes excessive oil production in skin and scalp, and excessive sweat production in sweat glands. Some experience this only at night and is commonly referred to as night sweats.

Hyperhidrosis can be caused by low dopamine levels associated with Parkinson's or from some antiparkinsonian medications. The low level of dopamine is linked to dysfunction in the autonomic nervous system that is responsible for regulating body temperature and can result in excessive sweating or reduced sweating.



Excessive sweating can disrupt daily activities, cause body odor, social anxiety and trouble sleeping.

What can be done to manage hyperhidrosis?

Medical and non-medical treatment options are available to manage hyperhidrosis. From a medical perspective, botulin toxin injections may be used to reduce sweating in specific areas. While electric current therapy (iontophoresis) can reduce the production in the sweat glands¹.



Some over the counter and topical treatments are available to help treat excessive sweating such as antiperspirants or topical creams containing aluminum chloride hexahydrate or anticholinergics.

Additional ways to help reduce sweating are:

- » Taking frequent, lukewarm showers to wash away excess sweat.
- » Wearing looser, breathable clothing (ex. cotton or linen) to help increase air flow.
 - If experiencing night sweats, light cotton bedding and sleepwear can help wick away sweat and provide a cooler sleep.
- » Drinking plenty of water to replenish fluids being lost from perspiration.
- » Avoiding triggers for excessive sweating (ex. spicy foods, alcohol, crowded rooms).
- » Lowering the thermostat at night and increasing air flow by using a fan can help reduce nighttime sweating.

Changes in sweating can be an uncomfortable symptom of Parkinson disease; disrupting daily activities and affecting quality of life; but the good news is that there are steps you can take to managing changes in sweating.



References

- ¹ Feddersen, Berend, Klopstock, Thomas, Noachtar, Soheyil
Neurology February 2005, 64 (3) 571; DOI: 10.1212/01.
WNL.0000145830.94572.2E

PROGRAM NEWS & UPDATES

To register for an upcoming Support Group or to put your name on a waitlist for upcoming programs please contact your regional Client Services Coordinator, call us toll-free at 1-800-561-1911, or email us at info@parkinsonassociation.ca. Be sure to include your name, phone number and program you are interested in/ registering for in the body of the email.

1:1 Physiotherapy

As some of you may be aware, we currently offer 1:1 physiotherapy sessions at our Edmonton Office. We are exploring the possibility of expanding this program in two ways: 1) offering virtual 1:1 sessions so regardless of where you live in Alberta you can have access, and 2) offering this same service at our Calgary office. 1:1 physiotherapy is a great option for those who are not interested in group exercise or who want help with a movement/exercise plan that is tailored to their challenges and interests.

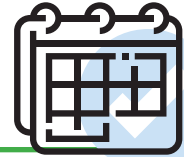
1:1 Occupational Therapy

Parkinson Association of Alberta is excited to announce that beginning this month, Connie Luu, MSc.A.OT will be offering 1:1 occupational therapy sessions both virtually and in person (in the Edmonton Office). As Parkinson's progresses, activities that were once easy to perform can become much more challenging. Connie can help you and/or your loved one maintain a sense of independence and continue participating in activities that bring you joy by providing assessment, insight, and practical solutions to challenges you may be facing.

Transition to CARE (runs May/June)

Caring for a loved one with Parkinson's does not stop when they begin to require more specialised support and you are no longer the primary caregiver; but it does begin to look and feel different. This part of the Parkinson's journey can often be quite challenging and emotionally charged, so we designed this program to provide support and assistance. Designed for those Care Partners whose loved ones are now in long term care, this 6-week online program will help you: deal with emotions and challenges that often come with this change, stay connected to your loved one, develop strategies to help navigate the transition, and advocate for your loved one in LTC.

WHAT'S
NEW?



Important Dates to Remember

All PAA Offices will be closed on the following dates:

April 15 & 18 (Easter)

May 4 & 5 (for in-person staff meetings)

May 23 (Victoria Day)

SAVE THE DATE

 **Parkinson**
Association of Alberta

2022 ANNUAL GENERAL MEETING

Be sure to purchase your Membership
by April 28 in order to vote!

Saturday, May 28 @ 11am

Virtual Zoom meeting with an in-person option in Edmonton

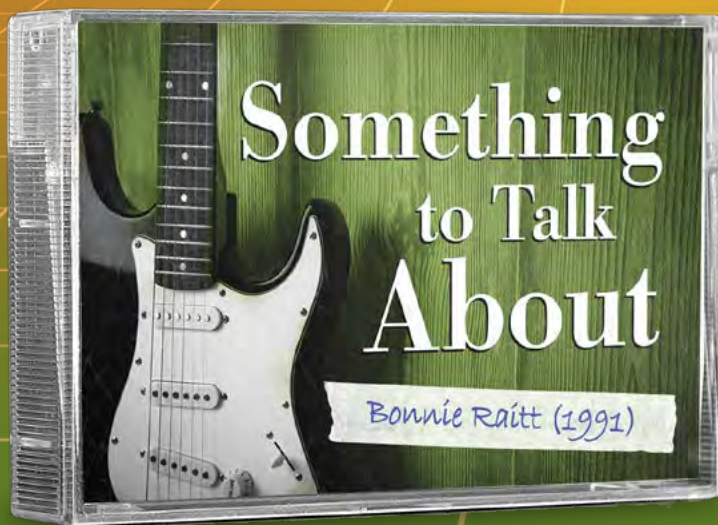
REMINDER: Advance registration is **required** every month, and for every support group you wish to attend. This ensures we can follow COVID protocols and contact people in the case of a cancellation or location change. Support groups may not run if no registrations have been received.

Please note that Support Groups will not run on statutory holidays.

To register please call toll-free **1-800-561-1911** or, talk to or email your Client Services Coordinator.

PROVINCIAL (ZOOM/CALL-IN ONLY) 1-800-561-1911	
1st Tuesday – DBS/Duodopa	1:00PM
1st Thursday – Widows/Widowers	10:00AM
2nd Monday – Care Partners AM	9:30AM
2nd Wednesday – Young Onset (Under 55)	7:00PM
3rd Thursday – General Parkinson's	10:00AM
3rd Thursday – Care Partners PM	1:30PM
3rd Saturday – Parkinson's Plus	12:00PM
CALGARY REGION	403-243-9901
AIRDRIE	
3rd Tuesday	10:00AM
CALGARY	
1st Tuesday – Northwest	10:00AM
1st Thursday – Northeast	10:00AM
3rd Tuesday – Care Partners (Zoom)	1:30PM
3rd Thursday – Southwest	10:00AM
4th Tuesday – Southeast	10:00AM
4th Tuesday – Central	7:00PM
CANMORE	
2nd Thursday	1:30PM
COCHRANE	
2nd Thursday	10:00AM
HIGH RIVER / NANTON / OKOTOKS	
4th Thursday	10:00AM
STRATHMORE	
1st Thursday	1:30PM
EDMONTON REGION	780-425-6400
CAMROSE	
2nd Wednesday	3:30PM
EDMONTON	
1st Wednesday – South	1:00PM
1st Thursday – Care Partners	10:00AM
3rd Wednesday – Central	7:00PM
FORT SASKATCHEWAN	
4th Tuesday	1:00PM
LEDUC	
4th Tuesday	6:30PM
PARKLAND (Spruce Grove / Stony Plain)	
4th Thursday	10:00AM

EDMONTON REGION...continued 780-425-6400	
SHERWOOD PARK	
2nd Tuesday	1:00PM
ST ALBERT	
3rd Tuesday	10:00AM
WESTLOCK (Zoom / Call-in)	
3rd Thursday	10:00AM
WHITECOURT (Zoom / Call-in)	
3rd Thursday	10:00AM
GRANDE PRAIRIE REGION	780-882-6640
GRANDE PRAIRIE	
2nd Wednesday	1:00PM
LETHBRIDGE & MEDICINE HAT REGION	403-317-7710 403-526-5521
LETHBRIDGE	
3rd Thursday	2:00PM
MEDICINE HAT	
4th Thursday	2:00PM
SOUTHERN ALBERTA (Zoom / Call-in)	
2nd Thursday	2:00PM
LLOYDMINSTER REGION	780-808-5006
BONNYVILLE	
3rd Tuesday	10:30AM
LLOYDMINSTER	
4th Tuesday	2:00PM
VERMILION	
1st Tuesday	10:30AM
RED DEER REGION	403-346-4463
CASTOR (Zoom / Call-in)	
3rd Thursday	10:00AM
LACOMBE	
4th Wednesday	10:00AM
OLDS	
2nd Wednesday	1:30PM
RED DEER	
3rd Wednesday	10:00AM
ROCKY MOUNTAIN HOUSE	
2nd Thursday (Jan, Mar, May, Sep & Nov)	2:00PM
THREE HILLS (Zoom / Call-in)	
3rd Thursday	10:00AM



Written By: **Brienne Leclaire**
With files from Ashley Ploof

Conversation is a valuable and necessary part of daily living. It is the foundation of social interaction, remaining connected and keeping feelings of isolation and loneliness at bay. Speech and voice issues are common occurrences for people with Parkinson disease, with research indicating 75-90% will develop problems over the course of their illness¹.

Parkinson disease affects the body's motor system, which means it affects the voice as well. From the diaphragm to the larynx to the face itself, a multitude of muscles are used in speaking. Though symptoms vary widely from person to person, the speech and voice symptoms most commonly demonstrated by people with Parkinson's are:



» **Reduced vocal loudness (soft voice or hypophonia)**

What is tricky about this one is that you may think you are speaking loudly, when in reality you are not.

» **Monopitch (lacking the normal variation in inflection)**

Typically, when people talk, voices go up and down in pitch, also known as inflection. In Parkinson's this inflection disappears and the voice sounds flat.

» **Disruptions of voice quality**

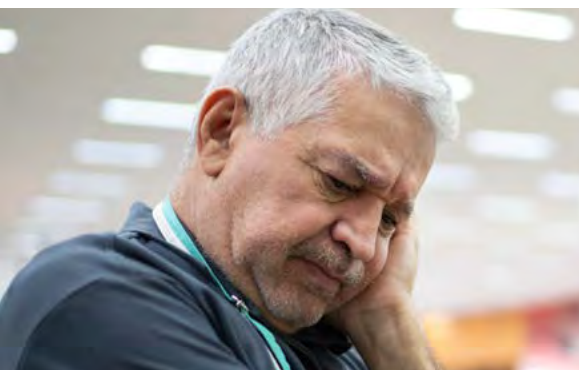
This could mean that your voice sounds hoarse, slurred, rough, or breathy.

» **Abnormally fast rate of speech**

In this instance the words seem to tumble out quickly almost over top of one another.

» **Fatigue in speech**

The voice may start off strong, however the longer one speaks volume and pronunciation decline.

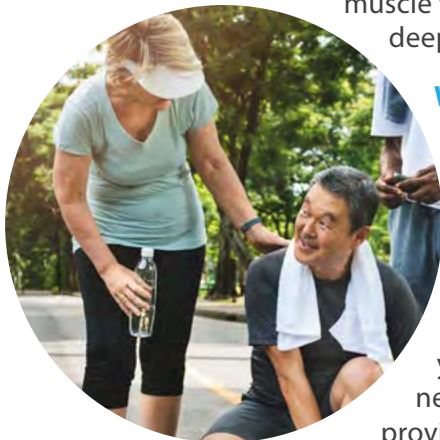


This cluster of symptoms is often termed "hypokinetic dysarthria". These issues can happen at any time and tend to increase as Parkinson's progresses.

Another aspect that can affect speech is one's cognitive abilities. Parkinson's can cause cognitive impairments that can affect one's ability to recall words, alter one's normal speech patterns and the production of speech. People with Parkinson's might find they struggle recalling or saying certain words. Described often as the feeling of a word being on the tip of one's tongue but unable to say or remember the word.



Vocal changes are not just part of Parkinson's but also a normal part of aging. These changes begin from around age 60 to 70. The muscles that produce sound called vocal folds get weaker and become less flexible. Changes also start to occur that can affect how efficiently one breathes. The maximum amount of air one's lungs can hold decreases, and the diaphragm (a muscle which helps us to breathe deeply) becomes weaker.



What can be done to combat voice and speech issues in Parkinson's?

Speech Language Pathologists (SLP) are an excellent resource if you have access to one near you. They can help by providing an assessment to find out more about the changes

happening with your voice and provide assistance in improving or maintaining your speech.

If you do not have access to a Speech Language Pathologist, there are vocal exercises that can help. There are also some things you can try on your own (or with a group) to incorporate into your day to aid in maintenance of your speech.

- Stay social! Having conversations with friends and family is one of the best things you can do for your voice. Go for coffee with friends, video call or talk on the phone; all of these keep your voice active.
- If you're reading something, read part of it out loud.
- Like music? Sing along to your favourite songs or join a singing group or church choir!

- Keep being active. Many people already incorporate physical activity into their daily routine, but exercise also keeps your lungs strong, which will help you maintain your voice.



Speech is often overlooked in the early stages of Parkinson disease. Sometimes it can be hard to recognize the small changes that are occurring early on in the journey. When you or your loved one starts to notice these changes, it is important to take care of your voice now to maintain your independence and relationships. Everyone has different goals in maintaining their voice. Some may want to continue things like reading stories to their grandchildren, singing, and being able to converse with loved ones. Others may worry about maintaining their independence through being able to speak for themselves in the future.

References

¹ Cleveland Clinic. "Tips for Improving Communication in People with Parkinson's Disease." <https://my.clevelandclinic.org/health/diseases/9392-speech-therapy-for-parkinsons-disease>. 2020-08.



Written By: **Brandi La Bonte**
With files from Ashley Ploof

Changes in vision are common as people get older. For those with Parkinson's, problems with eyes and eyesight are a little more complex than just "getting older". Parkinson disease does not cause vision loss, however it can lead to significant vision changes that directly impact day-to-day life (including watching tv, reading, etc). It is important to note that all of the Parkinson's related vision changes will impact driving to varying degrees. For those with Parkinson's Plus Syndromes, particularly Progressive Supranuclear Palsy (PSP) and Multiple Systems Atrophy (MSA), vision issues are more likely and often more severe.

Some of these issues include:

Reduced Blinking and dry eyes

This is one of the most common vision problems in Parkinson's. Did you know that most people blink 15-20 times/minute, but for people with Parkinson's that number is reduced by approximately 30%; and for those with PSP the number of blinks drops to 3/minute¹? The reduced blinking is caused by the general slowing down (bradykinesia) that happens with Parkinson's and often results in dry, sore, and tired eyes.

Blepharospasm

This phenomenon happens when the muscles that move your eyelids contract or go into a spasm. Caused by impaired electrical signals in the brain blepharospasm can result in excessive blinking or twitching of the eyelid or difficulty keeping your eyes open.

Blurred vision

This issue occurs either as a side effect of some Parkinson's medications (particularly anticholinergics), OR by difficulties moving the eyes (see the next point).

Eye Movement Issues

Your eyes are a moving part of the wonderful machine that is your body. Just like other parts of your body (legs, hands, etc) Parkinson's can affect your ability to move your eyes as well. You may begin to notice that you have difficulties when starting to move your eyes (left to right or up and down) or when trying to move them quickly. It may be more noticeable when looking at a fast-moving object, such as when watching moving cars or a tennis match. Sometimes, instead of a smooth movement, your eyes may move in a slow and jerky way. Issues with eye movement can make driving quite difficult, and depending on severity, very unsafe.

The three main types of eye movements affected are:

- **Saccadic** - the rapid movement eyes make that allow you to quickly change what you are looking at. An everyday example of this would be when reading a book and moving from one line to the next or shoulder checking while driving.
- **Pursuit** - the kind of movement eyes make when following an object either horizontally or vertically. The eyes typically move smoothly, instead of in jumps. In Parkinson's, these movements can become jerky. An everyday example in this case

would be drawing a line on a piece of paper or watching a grandchild throw a ball towards you.

- **Vergence** - the movement eyes make when an object moves towards or away from you, focusing naturally as that object moves towards or away from you or if an object is closer to you or further away. If these movements are abnormal in Parkinson's, it may cause double vision. Your everyday life is made up of these eye movements from driving, to walking, to preparing a meal or getting groceries.

Double (*diplopia*) vision

Double vision is pretty much what it sounds like — seeing two images of a single object some or all of the time. You may see the two images one on top of the other, side by side, or a mix of both. This is also often caused by problems moving the eyes. Typically, a side effect of medication but can also be attributed to dyskinesia. It should be noted however that not all instances of double vision are caused by Parkinson's. A head injury, diabetes or even astigmatism can also cause this.

Colour and Contrast Impairments

People with Parkinson's tend to have less sensitivity to contrast and colour. With contrast it is the ability to perceive the difference between light and dark areas. For example, a shadow may be perceived as a real object. The ability to distinguish colours from one another becomes impaired and can be particularly problematic with shades of blues and greens or more pastel colours. This is often caused by one or both of the following: 1) Parkinson's causes a loss of retinal cells in the eye that rely on dopamine to process and perceive colour², and 2) cognitive impairments can also play a role in this issue.

Spatial awareness

Some people with Parkinson's may have difficulty judging the space around them. They may not be able to gauge the distance between objects and may have problems when walking past objects or getting through a narrower space (like a doorway). Sometimes reaching out to touch the sides of doorways or other objects may help. In this instance it is likely not a medical professional who deals with eyes that can help you, rather an occupational therapist.



The good news is that depending on the specific issue, treatment options are available. These can include medication adjustments, eye drops or artificial tears, botulinum toxin injections, new glasses/contact prescriptions or even changing the lighting in a room.

Some other things that can help:

- » See your optometrist regularly for an eye exam.
- » You might consider getting two pairs of glasses, one for distance and one for reading instead of bifocals. (Talk to your optometrist about this option and why it might be helpful)
- » Use a warm moist compress to help with sore, tired eyes, and eyelid redness or irritation.
- » Try limiting screen time (tv, computer or phone) when you feel your eyes getting tired or sore.

Your neurologist will often assess vision as part of your ongoing neurological exams. However, if you notice any changes in your vision between appointments, your regular optometrist is a great place to start as they can provide a thorough exam. This of course, should be followed up with your neurologist at your next appointment. They can help you determine if there may be more health-help available with other medical professionals like an ophthalmologist or orthoptists.

References

¹ Hamedani, A and Gold, D. "Eyelid Dysfunction in Neurodegenerative, Neurogenetic, and Neurometabolic Disease," *Front. Neurol.*, 18 July 2017. doi.org/10.3389/fneur.2017.00329

² Dolhun R. "Vision and Parkinson's Disease," www.michaeljfox.org, 27 October 2015

APRIL IS

PARKINSON AWARENESS MONTH

At Parkinson Association of Alberta, this is our opportunity to raise awareness of this degenerative neurological condition and the impact it has on those who have received a diagnosis, the people who love and care for them, and our community as a whole.

This April, we will spread the message of **Hope through Research.**

Parkinson's is the fastest growing neurological disease in the world.

There's currently no cure.



Support for Parkinson Disease research in Alberta is extremely important. Alberta has much to offer in the effort to improve lives and progress to a cure for people living with PD, with exceptional institutions and highly regarding investigators. By supporting young scientist and healthcare professionals pursuing PD research in Alberta, PAA helps Alberta to continue to make valuable contributions to PD research. As well, it enables the development of the next generation of scientists and physicians with an understanding of the challenges of the PD journey. These individuals will play a vital role in the Alberta PD community for years to come. - Dr. Cara Ferreira, PhD



LUNCH & LEARN SPEAKER SERIES

NOON - 1PM
VIRTUAL

THEME: HOPE THROUGH RESEARCH

**Wednesday
April 6**

Life Space Mobility and Parkinson disease

Dr. Allyson Jones, PT, PhD and Charlotte Ryder-Burbidge, MSc

**Wednesday
April 13**

Learning About PD and PD+

Dr. Vikram Karnik, MD

**Wednesday
April 20**

Motivation to Move; Engaging Active Programming

Dr. Richard Camicioli, MD, FRCPC (Neurology)

**Monday
April 25**

Spotlight Alberta

Moderated by Dr. Davide Martino, MD

Featuring Dr. Veronica Bruno, MD, MPH and Raelynn Brassard, PhD candidate, U of A

**Wednesday
April 27**

Our Impact: PAA's Contributions to the AB Research Community

Moderated by Dr. Cara Ferreira, PhD

Kenneth Murdoch, MEd, RPsych; Dr. Jennifer Andrews, PhD; Dr. Taylor Chomiak, PhD
& Dr. Darren Clark, U of C

**Friday
April 29**

The State of Research in Alberta

Dr. Oksana Suchowersky MD, FRCPC, FCCMG

The PAA granting process and the 2022 awards recipients.

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While not a non-motor symptom, Dystonia can be a relatively common occurrence in Parkinson disease. It is important to note that dystonia can be present without the diagnosis of Parkinson disease. Dystonia is the term used to describe prolonged, involuntary muscle contractions that cause pulling of the muscles into abnormal movements and posture. These contractions are sustained and repetitive, which lead to pain from lack of relaxation of the muscles. When the dopamine producing cells deteriorate as a result of Parkinson's, the communication between the brain also becomes impacted. The signals communicated between the brain and the muscles become irregular leading to opposing muscles contracting involuntary at the same time and causing dystonic pain. The body ignores the natural response to relax the tightened muscles and the pain is prolonged for the individual with Parkinson's. The contractions can be initiated with intentional movements, such as exercising or walking, but can happen without intentional movements, such as laying down. It is common to initially notice the symptoms of dystonia during exercise, which is known as kinesigenic foot dystonia.



Dystonia can occur in multiple body parts, but most commonly in the feet. When dystonia occurs in the foot, it is often described as toes curling into a claw-like position, inversion (ankle turning inwards), plantar flexion (moving foot upwards or downwards), toes pointing upwards, or painful cramping. However, the pain associated with dystonia is unique to each person, just as their Parkinson's is unique to them. The symptoms typically occur on the same side of the body as the other motor symptoms of Parkinson disease. As the disease naturally progresses, the development or increase in dystonia can happen. Additionally, non-motor symptoms (depression, anxiety, and fatigue) can increase the occurrence of dystonic pain. As a result of dystonia, an individual's quality of life and ability to complete daily living tasks can be negatively impacted.

Dystonia is most common for those with Young Onset Parkinson's (diagnosed under the age of 50) and can be the first symptom an individual may experience, which eventually leads to their diagnosis. For the majority of people with Parkinson's the painful symptoms of dystonia are usually due to medication (usually Levodopa) wearing off or losing effect. For example, dystonia commonly occurs in the morning after a long overnight period without medication. During periods of wearing off, the other motor symptoms may return in addition to the dystonia. The painful effects of dystonia may be resolved once the morning medications have been taken. If dystonia occurs during on-periods of medication, it may signify too much dopamine in the system and overstimulation in muscles.

It can be difficult for individuals with Parkinson disease to mention dystonic pain to their health care team

because they're often unsure if the pain is related to Parkinson's. It's important to share this information with your medical team to ensure the right treatments are prescribed to reduce the impact on your quality of life. It can also be helpful to track the periods of dystonia to share with your health care team to find the right treatments.



Since the painful effects of dystonia are primarily caused by fluctuations in dopamine levels in the brain from medications, the treatments for dystonia include adjusting levels, doses, or timing of medication to reverse the effects. The treatment options can include many trial and error processes to find the right solution for each unique case. When dystonic pain occurs in the early mornings resulting from longer periods of time without medication, the treatment

may include controlled release (CR) versions of the medication to stabilize dopamine levels throughout the night. When the pain occurs throughout the day, the timing or dosing of medications may be changed to accommodate the periods of dystonia. The secondary treatment option available is the adjustment of medication routines to include additional dopamine agonists to increase the effectiveness and longevity of Levodopa medications. The other medications that can be added to the routine may include anticholinergic medications that target dystonia or muscle relaxant medications. One of the common treatments for dystonia is the injection of botulinum toxins (Botox) to paralyze the muscles, inhibit communication between nerves, stop contractions of muscles and reduce pain. The injections act as a strong muscle relaxant directly to the areas of the foot being affected. The use of botulinum toxins is a temporary solution, which requires follow up appointments every few weeks. The use of surgical interventions, such as deep brain stimulation (DBS) surgery may also be helpful in reducing pain from dystonia, when applicable.

Finally, individuals experiencing dystonia may utilize non-medical treatments to help with immediate pain, including massaging the foot, using bunion correctors to straighten toes, exercise, physical therapy or using a heated pad on affected areas. Dystonic pain can impact daily living, however the right combination of treatment options can ensure the pain is manageable for everyday!

A hand holding a black marker is shown in the foreground, with the word "VOLUNTEER" written in large, colorful, hand-drawn letters. The letters are in various colors: red, purple, blue, green, yellow, and orange. The background is a solid yellow color.

We have many great fundraising events taking place across Alberta this year, and we rely on the support of our amazing volunteer community to make each one a success.

But we need more volunteers to join the fun and help out!

**Call our Volunteer Coordinator today and get involved.
You'll be glad you did.**

1-800-561-1911

Transformative Technology Sparks Collaboration and Knowledge Exchange

Contributed By: *Lauren Bentley & Brain Canada*

Researchers are studying underlying biological mechanisms and testing new therapies to find more effective treatments for diseases like Parkinson's

One of the major limitations in finding treatments for brain diseases such as Parkinson's has been the difficulty acquiring appropriate tissue samples from patients.

"People will give you a bit of their blood or their skin, but they won't give you a piece of their brain," says Dr. Edward Fon, Scientific Director of the Early Drug Discovery Unit (EDDU) at The Neuro (Montreal Neurological Institute-Hospital).

But a promising technology developed in the past decade is changing that. The method involves

converting adult stem cells into what's called an "inducible pluripotent stem cell." These new cells can then be reprogrammed into desired cell types – like brain cells.

"Now, just from a blood sample, we can reprogram those blood cells into stem cells, and then make those stem cells grow into neurons, other types of brain cells, or even three-dimensional brain organoids, that have electrical activity and express the same kinds of genes that cells within a real brain do," says Dr. Fon.



Dr. Edward Fon



With these stem cells, researchers can study underlying biological mechanisms and test new therapies, with the hope of finding more effective treatments for diseases such as Parkinson's, ALS, and more.

Dr. Fon was part of a team, led by Dr. Jack Puymirat (Université Laval), that received a 2014 Brain Canada Platform Support Grant (PSG) to develop the Human Inducible Pluripotent Stem Cell (hiPSC) platform. The \$1.5 million grant helped make this transformative technology accessible to researchers across Canada.



In addition to helping lead the platform, Dr. Fon is a seasoned Parkinson disease researcher who will use the new technology to advance his work understanding the molecular events leading to the degeneration of dopamine neurons. He says he is excited by the potential for using the hiPSC platform to illuminate the mechanisms underlying Parkinson's.

Research in the neurosciences has always required a combination of skill, imagination, conviction, and insight. Increasingly, however, research also requires access to biobanks, clinical trial networks, drug discovery platforms, and shared facilities and equipment. These platforms play a critical role in fostering innovation and interdisciplinary collaboration. As such, access to platforms is imperative to address the evolving needs of high-impact research.



Brain Canada launched its PSG program after recognizing the essential need these collaborative platforms. By bringing together cutting-edge equipment, technology, and services and making them widely available, these platforms accelerate research outcomes beyond what a single researcher

might achieve with just the resources in their own lab. Through PSGs, Brain Canada continues to fill a critical gap in funding as it pertains to the development, operation, and maintenance of research platforms.

"Many brains are better than one," says Dr. Viviane Poupon, Brain Canada President and CEO. "When we work together to invest in platforms that facilitate innovation and interdisciplinary collaboration, we are convening experts across fields and enabling science to move a lot quicker."

"Brain Canada's initial investment and support of the platform was absolutely instrumental in getting things off the ground. Making these stem cells takes a huge number of resources. But this platform gives us significant economies of scale," says Dr. Fon.

Since receiving the 2014 grant, the hiPSC platform has evolved from a local project at the Université Laval into the Early Drug Discovery Unit (EDDU), an open drug discovery platform. The platform now serves researchers across Canada and has stimulated national and international collaboration.

Funding provided by Brain Canada has been made possible by the Canada Brain Research Fund (CBRF), an innovative arrangement between the Government of Canada (through Health Canada) and Brain Canada Foundation. To date, Health Canada has invested over \$130 million through the CBRF which has been matched by Brain Canada Foundation and its donors and partners.

**The views expressed herein do not necessarily represent the views of the Minister of Health or the Government of Canada.*

☐ **NEW \$35 Primary Membership**☐ **RENEWAL \$35 Primary Membership**

First Name: _____ Last Name: _____

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Select One: ☐ I am a Person Living with PD/PD+ ☐ Family Member/Friend☐ My Spouse/Partner has PD/PD+ ☐ Stakeholder/OtherI would like to receive updates from PAA: email news, Pulse Magazine by email **YES NO**I would like my Pulse Magazine mailed to me **YES NO**I would like to learn more about volunteering **YES NO**I want a staff member to contact me about PD and/or PD+ **YES NO**I want a staff member to contact me about Programs and Services **YES NO**

When you become a member, you are not just "buying a membership" with Parkinson Association of Alberta, you are investing in our Parkinson community to ensure there remains help for today and hope for tomorrow!

☐ **ADDITIONAL \$15 Secondary Membership**

Name: _____ Email: _____

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Select One: ☐ Spouse/Partner ☐ Family Member/Friend ☐ Stakeholder/OtherI would like to receive updates from PAA: email news, Pulse Magazine by email **YES NO****PAYMENT**

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Mail to: **PAA Calgary Head Office - 120, 6835 Railway St SE - Calgary, AB T2H 2V6**Or drop off at your **Regional Parkinson Association of Alberta Office**

SAVE THE DATES!



**Saturday, September 10 and
Sunday, September 11
across Alberta!**

Parkinson Awareness Month

Around the World,
April is **Parkinson
Awareness Month**.

This April, we will
spread the
message of
**Hope Through
Research.**

Join our **Lunch & Learn Speaker Series!**

These free noon hour webinars will give you a chance to hear from some of Alberta's leading researchers and heads of clinics, on topics ranging from innovations in research, education, and support, as well as personal stories from our Parkinson's community.

- **April 3-9:** Living with PD and PD+; Emotional and Practical Support
- **April 10-16:** Learning about PD and PD+; Educational materials and presentations
- **April 17-23:** Motivation to Move; Engaging active programming
- **April 24-30:** Investing in the Future; supporting Alberta-based research

● visit parkinsonassociation.ca for details ●