Parkinson Association of Alberta *Quarterly Magazine* **Summer 2022**

Parkinson PULSE

Connecting people living with Parkinson disease in Alberta

Parkinson's Plus Syndromes

Connecting the Pieces of Parkinson's Plus Syndromes

Parkinson Association of Alberta

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Parkinson Association of Alberta

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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Message from our Executive Director

Dear friends,

Summer is upon us but not before hitting us with some spring weather mayhem. I hope this edition of Pulse finds you well.

I wanted to express a word or two of thanks to the many talented guest speakers and webinar participants that made Parkinson Awareness Month such a success this year. We raised nearly $50,000 with the majority designated to support Parkinson's research in our province. We also learned so much about the research we've supported in the past and what's currently underway. More than 400 individuals took part in our month-long series!

Thanks to all our members who joined us at our Annual General Meeting at the end of May. Coming out of the worst of the pandemic, our organization remains strong and focused, with a thoughtful and skilled Board of Directors helping to guide the way. In addition to new programming and increased reach, we were pleased to be able to report a positive revenue position to close out 2021. You can find our full Report to the Community and Audited Financials on our website. We are truly grateful for the support of our community in this achievement.

With summer comes the launch of PAA's 10th Annual Step 'N Stride for Parkinson's. If you haven't been involved in the past, we invite you to learn more within the following pages or by visiting our website.

This fun walk is our organizations largest annual fundraiser but more importantly, a chance for our communities to connect and enjoy active social time together. I look forward to meeting more of you this September and thank you in advance for your fundraising efforts!

This edition of Pulse focuses on Parkinson's Plus Syndromes. There are currently estimated to be 100,000 people in Canada living with a Parkinson disease diagnosis. Approximately 15% of people who have been diagnosed with Parkinson disease will end up being diagnosed with a Parkinson's Plus Syndrome (atypical parkinsonism). These include Progressive Supranuclear Palsy (PSP), Multiple Systems Atrophy (MSA), Corticobasal Degeneration (CBD), and Dementia with Lewy Bodies (DLB) details of which our own Emma Torneiro has written about for this magazine. We hope you find the articles informative but please also know, our team is always available to answer any questions you may have.

Our best wishes for a peaceful and enjoyable summer,

Lana

Cover Story

Parkinson's Plus Syndromes

Written By: Brandi La Bonte

Did you know that Parkinsonism is the umbrella term used to describe a group of conditions that feature Parkinson's-type symptoms including tremors, stiffness and slowness of movement (bradykinesia)?

Most people (about 85%) with Parkinsonism have Idiopathic Parkinson's, more commonly known as Parkinson disease or PD. It is referred to as "idiopathic" because the cause is unknown in the majority of people diagnosed. The remaining 15% of people with Parkinsonism have other, more rare conditions known as either secondary parkinsonism or atypical parkinsonism. These terms are not diagnoses but simply indicate that the person likely does not have "ordinary" Parkinson's.

Secondary parkinsonism refers to a group of disorders that have features similar to those of Parkinson disease but have a different etiology (cause); these include drug-induced parkinsonism and vascular parkinsonism. Atypical parkinsonism refers to a group of neurodegenerative disorders other than Parkinson disease that have some features of Parkinson disease but different clinical features and a different pathology (structural and functional changes). We mainly refer to this type of parkinsonism as Parkinson's Plus Syndromes or PD+ and they include: Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA), Corticobasal Degeneration (CBD – also known as corticobasal syndrome), and Dementia with Lewy Bodies (DLB). Harder to diagnose because they (at first) mimic Parkinson disease symptoms, these four Parkinson's Plus Syndromes are definitively different diagnosis with their own unique and varying symptoms, treatments, and prognosis. It the latter, atypical parkinsonism/Parkinson's Plus Syndromes that are the focus of this magazine.

The last time we did a magazine on PD+ was 2017 and over the last five years we have noticed a few things.
1) the differences between PD and PD+ are significant and yet finding PD+ specific information can be challenging.
2) The ability to differentiate between the two (PD and PD+) has gotten better, which could account for the next point.
3) The number of clients we serve with PD+ has more than doubled since 2017.

The number of clients we currently serve who have (or love someone who has) a PD+ diagnosis is relatively small (4%) compared to PD. That 4% is no less important to us than the other 96% and so making sure that all the people we serve have access to the information, education and support that is best suited for their unique journey is vital. Our own Client Services Coordinator, Emma Torneiro, spent the last six months speaking with people with lived PD+ experience, medical professionals, and other PD organizations, as well as researching and reading everything she could find on Parkinson's Plus Syndromes. The result is this issue of Parkinson's Pulse - a compilation of information that is factual, thoughtful, relevant, and dedicated to those living with or loving someone with PD+. Thanks also to Dr. Choudhury and Declan Beddow, Client Services Coordinator, for their contributions.

Parkinson's Plus Syndromes are a different beast than Parkinson disease; with a clear diagnosis often harder give and/or taking longer to receive, a more rapid trajectory, and more challenges overall it can be easy to get overwhelmed and weighed down by the situation. It is important, no vital, to remember that support is available! We've got a specific PD+ support group, Client Services Coordinators who can answer your questions, provide emotional and practical support in 1:1s, and a variety of programming that can address symptoms affecting physical, cognitive, vocal, and social aspects of life. We are here to help you navigate this journey, every step of the way.

MSA Interview with Brad Doucette

Written By: Declan Beddow

As you have read through this magazine, we have provided information on what happens in the brain of someone living with a Parkinson's Plus Syndrome, the diagnosis process, symptoms and treatments but, what is it really like to live with a Parkinson's Plus Syndrome? Brad has agreed to sit down with us to share his firsthand knowledge and experience of living with Multiple System Atrophy (MSA).

Please note that the opinions expressed in this article are solely that of the client, and do not necessarily reflect those of Parkinson Association of Alberta. Quotes have been modified for brevity.

Declan Beddow (DB): *Can you tell us about your diagnosis journey with MSA?*

Brad Doucette (BD): Well, not that there is ever a good time to get this kind of news but, I got the diagnosis three days after I put it in my retirement papers at work, and two days before my 60th birthday. Worst birthday present ever.

Initially, I went to my family Doc for balance issues and the wild dreams I'd been having for quite some time. When she did the tests for the balance issues, she had to stop almost immediately because I almost fell over, and that's when I asked her about the dreams. She said, "I think it's all related."

So, I did the foolish thing, and I went on Google and I asked Dr. Google about "neurological dreams". The first thing that came up, of course, was REM behavior sleep disorder, which ultimately turned out that I did have. I worried about it for weeks, if not a couple of months, before I got in to see the neurologist.

The neurologist diagnosed me, and he gave me a booklet which turned out to be excerpt from the "Cure PSP" organization down in the States. He sent me home to read it and then said he'd call me in a few days to see if I had any questions. It was kind of an odd way to do that. I get kind of why he did, but it still left me with more questions than not. He also intimated that because MSA is so rare that the movement disorder clinic would probably want to look into my care because this is not a run of the mill disease. And so, he sent me for a second opinion.

Ultimately, after waiting months to receive a second opinion from them, I was not accepted as a patient at the movement disorders clinic, which was a big, sharp let down.

DB: *What would you recommend to someone who's newly diagnosed with MSA or what did you wish you knew when you first got diagnosed?*

BD: What I would recommend for somebody is get involved in your own care. First of all, know what kind of MSA you have, there are three kinds, and learn what the symptoms are early, so you know what your journey is going to look like.

For me, I knew early that with the cerebellar type MSA that I was going to eventually have trouble swallowing, breathing, and speaking. So, I got involved with the I CAN* program and they were very helpful with the voice banking and voice keeper programs. I got onto the voice keeper early, when I still could enunciate properly. I had some issues, but it's nowhere near what it is like now. I got my 500 recordings done and the voice that they came up with is actually quite good. So, I've got my voice, my synthetic voice, all stored away for when I may need it.

That would be something I'd rather do early. I know from the support group some people said they tried but that it was too late for them when they finally got around to it and they didn't get the full benefit. I'm also going to go see I CAN next week to see about some adaptive software and hardware for my computer. They have been a good, good resource for me so far.

DB: *Are there any treatments or any ways of managing MSA that you have found helpful?*

BD: I would say to get to physio right away so that you don't develop bad habits. I found that I'd started unconsciously slouching forward and I was looking over my feet a lot when I was walking, which was throwing everything off. I had one session with the Movement Disorder Clinic physiotherapist and she gave me some pointers and showed me some of the things I was doing that were causing issues. It was really good, and I think it helped me to not develop bad habits. Even some of the little tips like stand up straight, shoulders back, you know, move your arms at the same time as you walk - I didn't even realize I wasn't doing that. My balance became better. My walking became better. If I didn't get to that relatively early on, I would have taken a bigger nosedive.

The immune support piece would be another one. Get all the other systems in your body working well. That's why someone like a naturopath is a good way to go because they make sure your diet and digestive system is working the way that it should. They can help with some energy levels. There's just a bunch of stuff that they do that keeps things running smoothly. The immune system for me is very key in my day-to-day life. Strangely enough, I got a cold sore and just having the cold sore threw off my balance. I didn't recognize that the first or second time. I thought, well okay, now I know why I'm having a bad day today, it's because I've got a cold sore again. Just something simple like that. So, if you can get your immune system in shape, I think that is really key.

One of the things I also found was helpful was going on the clinicaltrials.gov site. You can put in what your condition is and it shows you all the clinical trials right around the whole world. It also tells you what they're working on and it does a pretty good job of explaining the mechanism of the disease that they are trying to counteract. So, I found that quite informational too.

DB: *Is there anything else you would like to add?*

BD: Initially, I didn't know where to look or where to go to get the kind of information and I was looking for. So, the other thing that I would recommend, is go to the support group. That's a good place to get information as there's so little out there about Parkinson's Plus. To actually hear from the people and families that are going through it is key, because it's a shared experience.

Lastly, we're dealing with the more immediate stuff rather than focusing on the pretty crappy stuff that's coming down the road. We're enjoying the day to day and taking each day as it comes. Spending lots of time with the grandkids and, you know, happy stuff. So that's what were focusing on.

Thank you to Brad for providing such detailed insight into the day-to-day considerations of those living with MSA. If you would like more information on the resources mentioned in this article, please contact your client services coordinator.

* I CAN Centre for Assistive Technology Service at the Glenrose Rehabilitation Hospital in Edmonton. The Augmentative Communication and Educational Technology Service (ACETS) is a similar program based out of the Alberta Children's Hospital in Calgary. *These programs are accessible by referral from a GP, neurologist, or healthcare professional* ***only***.

So many ways to support

Parkinson Association of Alberta

You want to contribute to the ongoing work of supporting people living with or loving someone with Parkinson disease and Parkinson's Plus Syndromes. Parkinson Association of Alberta offers options!

Our programs are designed to add a sense of community and inclusion with a suite of emotional, practical, educational and active opportunities that help people stay connected and live well longer. These programs are made possible by people like you.

Make a one-time or recurring donation

Funds are used in real time, which means your donation will be put to work as quickly as possible for maximum impact.
Recurring gifts — of any size — enable PAA to budget efficiently, plan for the future, and respond to emerging needs.

Planned giving: Your continued impact and legacy of investment in work that is meaningful to you may be done in a number of ways.

Charitable Bequests

By naming Parkinson Association of Alberta in your will, you will continue to impact the quality of life for people living with Parkinson's.

Gifts of Securities

Your gift of stocks, bonds, and mutual funds entitles you to a charitable tax receipt, while also adding impact to our community. This credit can result in significant savings and may be used in the year in which the donation was made or held back for future returns.

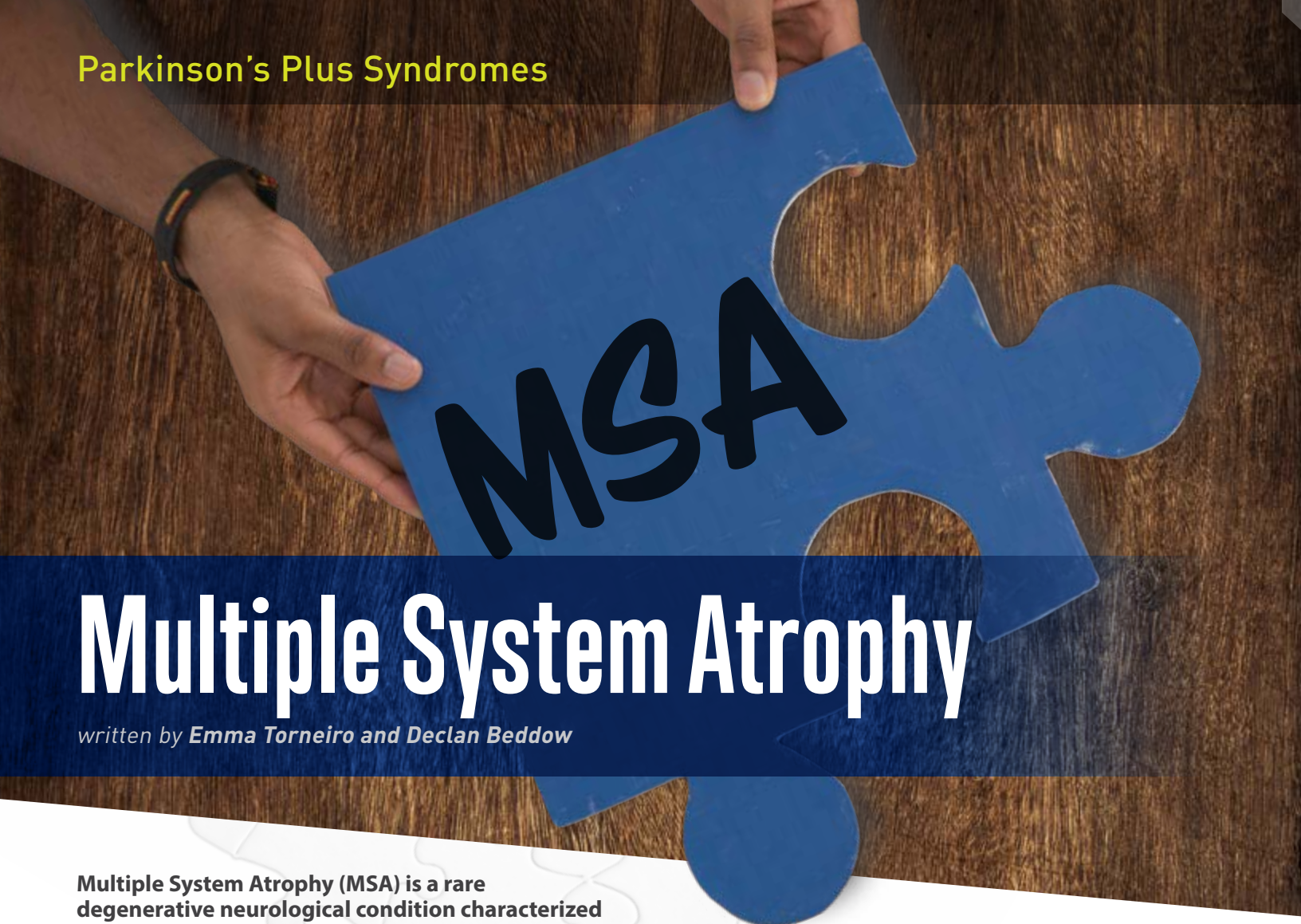
Life Insurance

You can have meaningful impact with your life insurance policy by naming Parkinson Association of Alberta as the beneficiary of either your current or a dedicated new policy.

Whether you are giving in memory or in celebration of a loved one, hosting a fundraiser, or organizing a workplace or social giving campaign, your support matters.

Parkinson Association of Alberta is privileged to support more than 2,500 individuals and their families annually. With nearly 15,000 people in Alberta living with a Parkinson's diagnosis today, a number that is expected to double in the next 10 years, your investment is needed to ensure we can continue to expand our reach.

With no permanent or consistent funding from outside sources, Parkinson Association of Alberta relies on the recognition and generosity of individuals, foundations, corporations and all levels of government to ensure our community of support remains available to all. Thank you for your ongoing investment in improving the lives of those impacted by Parkinson disease and Parkinson's Plus Syndromes.



Multiple System Atrophy

written by ***Emma Torneiro and Declan Beddow***

Multiple System Atrophy (MSA) is a rare degenerative neurological condition characterized by abnormal accumulation of alpha-synuclein protein (synucleinopathy1,2) in brain cells.

The alpha-synuclein protein is responsible for the transmission of messages between our brain cells and bodies[3]. What does this really mean? The alpha-synuclein protein creates clusters in the brain cells and disrupts the transportation of vital messages for bodily functions and movements. In MSA, shrinkage (atrophy) also occurs in parts of the brain responsible for movement and control. The onset of symptoms stems from the progressive loss of nerve cells in the brain and spinal cord[4,5]. The atrophy and protein accumulation lead to the motor, autonomic, speech, vision, and cognitive symptoms of MSA. The disease was initially described in 1969 as the Shy-Drager Syndrome stemming from the early contributions of the physicians Dr. Milton Shy and Dr. Glenn Drager.

The three types of MSA are Parkinsonian, Autonomic, and Cerebellar, which are differentiated by their associated symptoms. The Parkinsonian type (MSA-P) describes the presence of typical Parkinson symptoms (e.g., stiffness, rigidity, bradykinesia) with a degree of cerebellar dysfunction. The Autonomic type (MSA-A) describes dysfunction of autonomic nervous system (e.g., blood pressure, respiration, urination, digestion) with symptoms impacting involuntary functioning. Lastly, the Cerebellar type (MSA-C) describes symptoms connected to coordination, speech, and symptoms impacting voluntary movements.

There are many overlapping symptoms between MSA-P, MSA-A, and MSA-C, leading to the general classification of MSA. Similarly, to Parkinson disease (PD), the cause of MSA is unknown and there is currently no cure for the disease. The disease occurs sporadically, as it currently lacks genetic or environmental risk factors.

The diagnostic process for MSA involves an examination of personal medical history, symptoms, autonomic testing (primarily blood pressure), assessment of bladder functioning, and brain imaging scans (e.g., MRI for shrinkage or PET for metabolic function)[4]. Due to the scans being unable to differentiate between PD and MSA, many individuals initially receive a PD diagnosis. The diagnosis typically changes upon the recognition of faster progression by the healthcare team.

The Facts

- The average age of onset is 54
- Life expectancy is 7-10 years following symptom onset
- Prevalence is 6 people per million per year

Motor Symptoms

- Parkinsonian symptoms
- Difficulty initiating movement
- Action or coarse tremor, resulting in irregular movements
- Myoclonus (*rapid, jerky, and irregular movements in limbs or trunk*)[3]
- Earlier detection of postural instability comparative to PD
- Cerebellar Dysfunction
  - Incoordination in limbs, posture, and gait
  - Gait ataxia (*wide, irregular steps*)
  - Unsteady balance
  - Increased falls
- Pyramidal Tract Syndrome (*decrease in fine motor coordination*)[2]
- REM Sleep Behavior Disorder (*vividly acting out dreams*)
- Contractures (*chronic shortening of muscles around joints limiting movement*) in hands or limbs
- Pisa Syndrome (*curvature of spine or leaning towards one side*) similar to the Leaning Tower of Pisa[2,4]
- Antecollis (*a position where one is not able to keep their head up and looking forward, rather head is bent forward looking at the floor, forward flexion of neck*)[4] and inability to keep head lifted
- Camptocormia (*a "hunched" forward position, forward flexion of spine*)[2]
- Dystonia

Autonomic Dysfunction Symptoms

- Fluctuations in blood pressure
  - Orthostatic Hypotension (*low blood pressure when changing positions*)
  - Supine Hypertension (*high blood pressure when laying down*)[1]
  - Nocturnal Hypertension (*high blood pressure when sleeping*)
  - Fainting and Light-headedness
- Urinary incontinence, retention, or urgency
- Erectile dysfunction, impotence, bladder dysfunction, and constipation
- Nocturnal Stridor (*narrowing or obstruction of upper airways outside of chest cavity identified by strained high-pitched sound*)[2] or obstructive sleep apnea
- Anhidrosis (*reduced production of sweat, tears, and saliva*)[2] leading to heat intolerance and dry skin
- Inability to regulate body temperature, leading to color and temperature changes in hands and feet
- Inability to control emotions and expression of emotions (*laughing or crying at inappropriate times*)
- Irregular breathing patterns and heart rate patterns[3]
- Insomnia
- Involuntary sighing or gasping[4]

Vision Symptoms

- Blepharospasm (*twitching of eyelids*)
- Vertical Gaze Palsy (*limitations of eye gaze upwards or downwards*)
- Nystagmus (*involuntary, rapid, and jerky movements of eyes*)[6]
- Impaired vestibular-ocular reflex[6]
- Reduced accuracy of vision
- Double or blurred vision
- Visual hallucinations

Speech Symptoms

- Dysarthria (*difficulty with speech*)
- Slurred speech
- Dysphagia (*difficulty swallowing*)
- Hypophonia (*soft speech*)

Cognitive Symptoms

- Mild Cognitive Impairment
- Difficulties with Executive Functioning (*organizing information, understanding instructions, and decision-making processes*)

Treatment Options

There is no specific medication to treat MSA or slow the progression of symptoms, therefore treatments target management of symptoms and related conditions. The Parkinson's medication, Levodopa Carbidopa, may initially improve motor functions (slowness and stiffness) with benefits being limited as disease progresses. The healthcare team can also prescribe additional medications to manage the treatable conditions of MSA (e.g., erectile dysfunction, bladder control, blood pressure, myoclonus, dystonia).

The main treatment options for MSA focus on using therapies for management of symptoms and improve quality of life. The recommended therapies include physiotherapy for issues with balance and gait, occupational therapy for assessment of mobility aids and improvements to functional abilities, and speech therapy for challenges with speech, swallowing, and communication. The use of a dietitian is beneficial for help with proper nutrition, finding easy to swallow diets, and managing blood pressure. Finally, psychologist or social workers can provide support for the non-motor symptoms associated with the diagnosis.

Resources

1 *Multiple system atrophy (MSA). (2021, May 21). Mayo Clinic. Retrieved March 2022 from https://www.mayoclinic.org/diseases-conditions/multiple-system-atrophy/symptoms-causes/syc-20356153*

2 *Multiple System Atrophy. (n.d.). National Organization for Rare Diseases (NORD). Retrieved March 2022 from https://rarediseases.org/rare-diseases/multiple-system-atrophy/*

3 *Golbe, L.I. (2019). MSA: Some Answers. CurePSP. https://www.psp.org/wp-content/uploads/2021/04/2019-MSA-SOME-ANSWERS-BROCH_web.pdf*

4 *Multiple System Atrophy Fact Sheet. (2022, April 15). National Institute of Neurological Disorders and Stroke. Retrieved March 2022 from https://www.ninds.nih.gov/health-information/patient-caregiver-education/fact-sheets/multiple-system-atrophy-fact-sheet*

5 *Multiple System Atrophy. (2014, November). National Institute of Neurological Disorders and Stroke. Retrieved March 2022 from https://web.archive.org/web/20160406203452/http:/www.ninds.nih.gov/disorders/msa/multiple_system_atrophy_pamphlet.pdf*

6 *Armstong, R.A. (2014). Visual signs and symptoms of multiple system atrophy. Clinical and Experimental Optometry, 97(6), 483-491. https://doi.org/10.1111/cxo.12206*

PROGRAM NEWS & UPDATES

Summer Socials Return!

Summer Socials, our fun, outdoor social gatherings replace support groups over the months of July and August. Call your Client Services Coordinator, call us tollfree at 1-800-561-1911, or click on the "Program Calendar" box on the homepage of our website to find a Summer Social near you. Don't forget to call and register so that our staff can contact you directly if there has been a change in venue or cancellation due to weather.

7 Provincial Support Groups ALL Summer Long!

For those who can't make it to a Summer Social or are still looking for a more formal Group during the Summer months we have 7 online Support Groups to choose from: General Parkinson's (all welcome), 2 Care Partners Groups, DBS/Duodopa Group, Parkinson's Plus (PD+) Group, Young Onset (for those who are in their 50s or under), and a Southern Alberta Group.

1:1 Occupational Therapy

We are excited to announce that Connie Luu, our Occupational Therapist will be offering FREE 30-minute assessments both virtually and in person (in the Edmonton Office). 1:1s are available for booking all summer long! 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.

1:1 Physiotherapy

PAA currently offers 1:1 physiotherapy sessions at both our Edmonton and Calgary Offices. 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.

NEW Volunteer Section on our Website!

Find out how YOU can help make a difference in the lives of people affected by Parkinson's! Our new Volunteer section has all the latest news, opportunities, and information!

Important Dates to Remember

All PAA Offices will be closed on the following dates:

July 1 *(Canada Day)*

August 1 *(Heritage Day)*

September 5 *(Labor Day)*

October 10 *(Thanksgiving)*

Please note *there will be* ***no programs, Summer Socials*** *or* ***Support Groups*** *running between August 29 through September 9 as the whole Team prepares for the* ***10th Anniversary of Step 'n Stride!!!*** *Client Services Coordinators are still available for 1:1s and any support you might need of questions you may have.*

Call **1-800-561-1911** or email **volunteer@parkinsonassociation.ca**

Day-to-Day with Parkinson's, an Occupational Therapist Can Help

Written By: Brandi La Bonte
Puzzle created by: Connie Luu, OT

Occupational therapists (also known as OTs) can be an excellent resource for individuals living with Parkinson disease or Parkinson's Plus Syndromes. Whether you are having difficulty with your handwriting, experiencing cognitive changes, or having difficulties with self-care or even home management, occupational therapists can work with you to solve these problems so that you can continue doing these tasks in a way that is satisfying and meaningful to you. Similar to other members of your Parkinson's Care Team, occupational therapists help to promote independence, improve quality of life, and enable individuals to participate in meaningful and enjoyable activities.

By working with you, an occupational therapist will help you to identify your personal goals and tailor treatments to meet your unique needs. General goals of treatment sessions include goal setting, adapting environments, removing barriers, modifying tasks, restoring existing skills, or developing new skills. In order to achieve your goals, an occupational therapist will encourage you to use a high level of conscious attention when performing various activities and may incorporate cognitive and sensory 'cues' that may help you perform activities and complete tasks more easily.

Manual dexterity is the most prevalent reason why people with Parkinson's will seek help from an occupational therapist. Primary concerns for a person with Parkinson's can include reduced coordination, decreased fluidity of movement, and delayed reaction time to name a few. In order to address these issues, an occupational therapist may encourage you to participate in task-specific training exercises (ie: through big, powerful movements) or they may promote adaptive alternatives such as weighted utensils, large buttons, or rocker knives to make daily activities easier.

Occupational therapists can also help manage Parkinson's symptoms including fatigue, cognitive concerns, communication problems, and anxiety.

If you are having concerns regarding accessibility and completion of day-today activities within your home, an occupational therapist can provide a home assessment and offer guidance on home adaptations or equipment purchases that can eliminate some of the challenges you are experiencing. They may suggest using mobility devices, different gadgets or strategies, or even practical changes such as how to rearrange your furniture that can make moving around easier.

Occupational therapists work in a variety of settings including hospitals, community health centres, clinics, and within a clients' home. Parkinson Association of Alberta is pleased to have Connie Luu, OT, on our Team to provide these services both in-person (in select locations) and online across Alberta. Occupational therapists can also be accessed through Alberta Health Services, the Society of Alberta Occupational Therapists and the Canadian Association of Occupational Therapists. Individuals can either self-refer or be referred by a doctor. Depending on the service provider, some fees may apply.

OT Puzzle

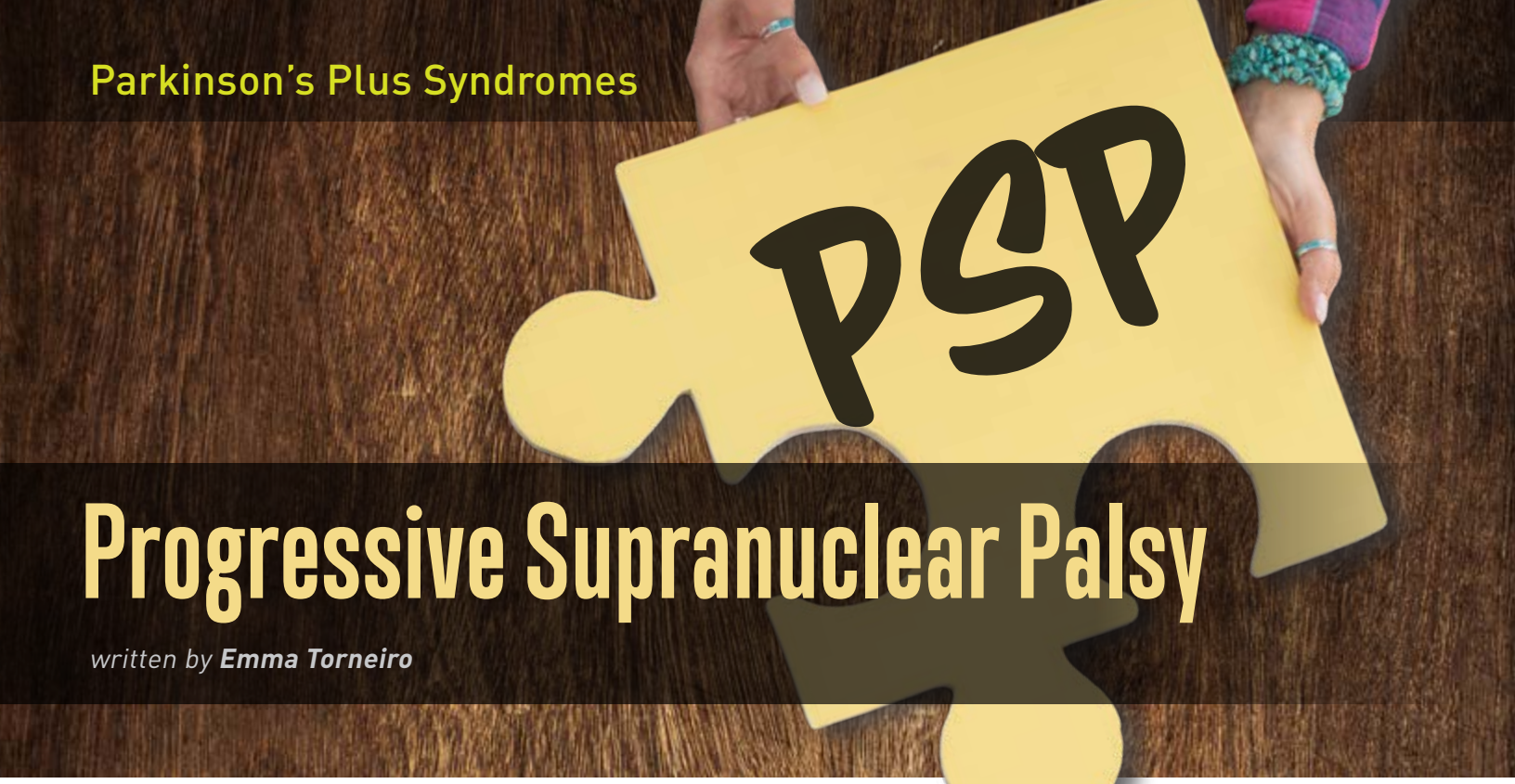
1. Find all of the words - words can go in any direction and may share letters.
2. Copy unused letters starting from the top left corner to reveal the hidden message.

If you are having difficulty with doing any of these activities independently or safely, you may benefit from:

_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

Budgeting
Cooking
Dressing
Typing
Drinking
Driving
Eating
Volunteering
FallPrevention
Gardening
Handwriting
Memory
Painting
Reading
Shopping
Showering
Sleep

G	O	C	C	G	G	G	U	P	A	T	N	I	O	R
N	N	A	L	N	N	T	H	E	R	S	O	A	P	E
I	Y	Z	I	I	U	J	D	Y	H	K	I	X	G	A
S	N	T	P	K	B	Y	P	O	I	G	T	G	N	D
S	A	Y	O	O	R	K	P	O	N	G	N	Q	I	I
E	T	B	J	O	D	P	D	I	N	I	E	G	T	N
R	J	N	M	C	I	R	R	I	R	D	V	A	N	G
D	P	E	F	N	I	E	T	E	S	R	E	R	I	Q
V	M	D	G	N	W	I	E	G	C	I	R	D	A	P
H	Y	H	K	O	R	T	G	I	P	V	P	E	P	C
T	Z	I	H	W	N	C	A	C	E	I	L	N	F	W
A	N	S	D	U	O	F	S	A	E	N	L	I	M	V
G	N	N	L	K	X	T	O	C	L	G	A	N	K	T
O	A	O	Z	C	I	I	G	D	S	V	F	G	V	V
H	V	X	A	B	U	D	G	E	T	I	N	G	R	D



Progressive Supranuclear Palsy

written by ***Emma Torneiro***

Progressive Supranuclear Palsy (PSP) is a rare neurodegenerative tauopathy condition resulting from abnormal buildup of tau protein in the brain causing cell death[1].

What do these medical terms really mean? In PSP, the cell degeneration and symptoms are caused by the malfunctioning of clumped tau protein (tauopathy) in the brain. The term progressive refers to the development over time, supranuclear refers to the vision issues and the areas of the brain impacted, and palsy refers to weakness or paralysis of muscles/body[2]. The motor and cognitive symptoms associated with PSP are connected to the deterioration of cells within the substania nigra responsible for movement, thinking, and coordination. The vision symptoms of PSP results from impairments to the facial muscles responsible for controlling eye movements[2].

The condition was initially titled Steele-Richardson-Olszewski syndrome in 1963 after the Canadian physicians who defined it[3]. The cause of malfunctioning tau protein and cell death in PSP is currently unknown, however research has furthered our understanding of the processes within the brain. The tau protein, which appears in all our brains, is primarily responsible for holding structures called microtubules together and transporting messages of movement between our brain and skeletal system. The microtubules are responsible for cell growth, movement, and cellular transport. In PSP, the tau protein clumps into knots called neurofibrillary tangles and the microtubules separate, leading to the dysfunction of the protein[3]. This means that clumps of tau protein are floating within the brain, leading to the brain being unable to send accurate messages for movement to the body and being unable to promote cell growth. The initial clump of tau protein creates a blueprint for future tau proteins and continues the chronic cycle of clumping and degeneration[3].

PSP is categorized into two main types: Richardson's Syndrome and PSP-Parkinsonism (PSP-P)[3]. The Richardson's Syndrome form primarily involves balance and gait problems. The form can also involve issues with speech, cognition, and vision. The secondary form, PSP-P, resembles Parkinson disease (PD) with more impactful tremor and followed by the Richardson type symptoms. The condition differs from typical Parkinson's through frequent, unexplained falls and difficulties with vision occurring 2-3 years after diagnosis[3]. The second difference between PD and PSP is the number of systems in the body being impacted. For example, PD only involves the dopamine systems within the brain, but PSP involves deficiencies in multiple systems with increased damage to brain cells[3].

The diagnostic process for PSP involves an examination of symptoms and may include brain imaging scans (e.g., MRI for shrinkage or PET for changes in brain). For many, the diagnosis process begins by investigating the loss of balance while walking and increased falls[3]. Due to the scans being unable to differentiate between conditions and the Parkinsonian symptoms, it is common to initially receive a Parkinson diagnosis. The process of diagnosing generally does not include examinations of familial medical history, as PSP is rarely genetic or hereditary.

The Facts

- The average age of onset is 45-70
- Life expectancy is 7-10 years following symptom onset
- Prevalence as the most common form of Parkinson's Plus Syndromes is 5-7 per 100,000

Motor Symptoms

- Parkinsonian symptoms
- Difficulties with Gait
  - Loss of balance and walking challenges
  - Freezing
  - Tendency to fall backwards
- Axial Rigidity (*straight posture or tilting head backwards*)
- Unilateral, action tremor known as PSP tremor[3]
- Dystonia

Vision Symptoms

- Blepharospasm (*involuntary closing of eyelids or increase in blinking*)
- Eye Apraxia (*difficulty coordinating vertical eye movements*)
- Photophobia (*sensitivity to bright lights*)
- Inability to focus eyes resulting from palsy in eye muscles
- Reduction in blinking, leading to dry eyes and loss of clarity from surface damage
- Loss of corneal sensitivity, leading to progressive damage of eye and increased difficulties blinking
- Difficulty shifting vision downwards, creating difficulty in daily living tasks (*e.g., eating, reading, driving*)
- Difficulty maintaining eye contact during interactions or conversations
- Tunnel Vision
- Double Vision
- Square Wave Jerks (*rapid, involuntary vertical eye movements*)[3]
- Supranuclear or Vertical Gaze Palsy

Speech Symptoms

- Dysarthria (*difficulty with speech*)
- Slurred speech
- Dysphagia (*difficulty swallowing*) with solids and liquids from incoordination and weakened muscles
- Hypophonia (*soft speech*)
- Aphasia
- Spastic speech (*inability to articulate or irregular speech patterns*)
- Ataxic speech (*speech has qualities of "drunken speech"*)[3]

Cognitive Symptoms

- Dementia
- Personality Changes (*e.g., lack of interest in activities previously enjoyed or increased irritability*)
- Slowness in mental processing, which creates challenging engaging in conversation due to delayed responses
- Inability to control emotions and expression of emotions (*laughing or crying at inappropriate times*)
- Difficulties with Impulse Control
- Difficulties with Executive Functioning (*organizing information, understanding instructions, and decision-making processes*)

Treatment Options

There is no specific medication to treat PSP or slow the progression of symptoms, therefore treatments target daily management of symptoms. The Parkinson medication, Levodopa Carbidopa, prescribed in a higher dose may initially improve the motor functions of PSP-P with benefits being limited to 2-3 years after diagnosis[3,4]. The secondary Parkinson medication that could provide limited relief for gait challenges is Amantadine[3]. The healthcare team can also prescribe additional medications (*e.g., depression, anxiety, dystonia*) and may provide recommendations for the vision symptoms of PSP (*e.g., Yoked Vertical or Horizontal Prism lenses or artificial tears*[5]).

The main treatment options for PSP focus on using therapies for management of symptoms and improvements to quality of life. The recommended therapies include physiotherapy for mobility and balance, occupational therapy for assessment of mobility aids, and speech therapy for challenges with speech, swallowing, and communication. The use of a dietitian is beneficial for help with proper nutrition and finding easy to swallow diets. Finally, psychologist or social workers can provide support for the non-motor symptoms associated with the diagnosis.

Resources

1 *Progressive Supranuclear Palsy. (n.d.). National Organization of Rare Disorders (NORD). https://rarediseases.org/rare-diseases/progressive-supranuclear-palsy/*

2 *Progressive Supranuclear Palsy. (2020, October 23). Cleveland Clinic. Retrieved from https://my.clevelandclinic.org/health/articles/6096-progressive-supranuclear-palsy*

3 *Golbe, L.I. (2021, July). PSP: Some Answers. CurePSP. https://www.psp.org/wp-content/uploads/2021/08/2021-PSP-SOME-ANSWERS-BROCH_web.pdf*

4 *Progressive Supranuclear Palsy. (n.d.). Mayo Clinic. https://www.mayoclinic.org/diseases-conditions/progressive-supranuclear-palsy/symptoms-causes/syc-20355659*

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Dementia with Lewy Bodies

Written By: Dr. Parichita Choudhury

Dementia with Lewy Bodies (DLB) is a complex disorder with symptoms overlapping with Parkinson's disease dementia and Alzheimer's disease. Among well-known people in the society, Robin Williams was diagnosed with DLB.

What Causes DLB?

Alpha-synuclein, an abnormal protein, accumulates in the brain causing toxicity and brain injury, leading to degeneration of the brain. They deposit in the brain cells (*neurons*) and are called "Lewy bodies" under the microscope. This is the same protein found in the brains of people with Parkinson's Disease. People with DLB frequently also have evidence of co-existent proteins of Alzheimer's Disease (Amyloid and Tau).

Who gets DLB?

Autopsy studies have shown that amongst degenerative forms of dementia, DLB is the second most common after Alzheimer's disease affecting cognitive function. DLB appears to affect more men than women in some studies although this is still under investigation. DLB is more common in people over the age of 65 and average age of diagnosis is 74.

What are symptoms of DLB?

The cognitive symptoms in DLB can be very similar to Alzheimer's disease with primarily memory loss, although some studies have shown that challenges with processing information, particularly visual information is also common.

To diagnose someone with DLB, two out of the following must be present in addition to cognitive symptoms:

1. REM sleep behavior disorder (acting out their dreams,)
2. Fluctuations in mentation lasting hours to days (between clarity of thought and lethargy/drowsiness)
3. Parkinsonian motor features (tremors, decreased balance, slowing or shuffling) and
4. Visual hallucinations (frequently of people or animals).

People with DLB may start out with any combination of these symptoms which makes it very challenging to diagnose. They may also have other associated symptoms such as orthostasis (lightheadedness), urinary problems, constipation, lack of sense of smell (hyposmia), depression, anxiety, and other changes in mental health.

Impact of DLB

DLB is commonly underdiagnosed and mis-diagnosed because of its similarities to both Parkinson's Disease and Alzheimer's Disease. There is also no one test that can help physicians diagnose DLB. However, the diagnosis is important because some drugs, particularly anti-psychotics, can cause a harmful reaction in people with dementia. There is also a higher frequency of delirium and hospitalizations.

What are some treatment options?

The treatment for DLB is multi-pronged. For cognitive symptoms, donepezil (drug for Alzheimer's disease) is used. It helps with the symptoms of thinking, but doctors also find that it can sometimes help with visual hallucinations and fluctuations. If you have parkinsonian movement problems, drugs like levodopa-carbidopa maybe used for treatment. Sleep disorders such as REM sleep behavior disorder can be treated with melatonin or clonazepam. Symptomatic treatments are also available for symptoms of bladder, bowel, and lightheadedness.

Drugs are not the only form of treatment to consider. Patients can also benefit from physical therapy, occupational therapy, and voice therapy.

Care Partner Advice

Tips for Caring for Loved Ones with Parkinson's Plus Syndromes

By: Emma Torneiro, James McClelland, Ken Cromer, and Laurel-Anne Millis

The role of care partner and/or caregiver is never an easy journey to navigate and often comes without a roadmap for the unpredictable conditions of Parkinson disease or Parkinson's Plus Syndromes. Each day brings a new challenge to manage together but can also bring special moments and memories with loved ones.

When the journey with a Parkinson's Plus Syndrome becomes accelerated due to a more rapid progression and limited response to medications, the role of caregiving becomes essential. The caregivers become the navigators, the advocates, the motivators (sometimes feeling like a constant nag) and the voice for their loved ones, while most importantly still being their spouse. At Parkinson Association of Alberta (PAA), we recognize the essential role of care partners and caregivers and feel honored to continue to support them and their loved ones managing Parkinson's Plus Syndromes.

I had the opportunity of virtually sitting down with James, Ken, and Laurel-Anne, three of our care partners, who shared their knowledge and perspective on caring for loved ones with Parkinson's Plus Syndromes. Together, we've created a list (modified for brevity) of advice and tips for caregivers to keep during their difficult but rewarding journey.

1. Be patient and compassionate with each other
2. Find a balance between addressing your loved one's needs and your own self-care
3. Try to take each day at a time – don't get too far ahead of yourself because there are no roadmaps for progression
4. Maintain open communication throughout the journey between your loved one, yourself, and the health care team
5. Develop communication strategies early (e.g., letterboard or tablet with common phrases) as verbal abilities are likely to decrease with progression

6 Be actively involved in your loved one's care, including accompanying them to all medical appointments

7 Create and maintain a compassionate healthcare team for your loved one

8 Try meeting your loved one's requests in the safest way possible, including different modifications or adaptations, and try managing issues as they arise, regardless of prognosis

9 Expect times of total frustration and depression, but also times of deep love and connectedness

10 Learn to accept help from others to allow respite for yourself as a caregiver and/or learn to ask for help with specific tasks

11 Access resources and supports available through Alberta Health Services (e.g., Home Care services) to take on some day-to-day tasks so you can focus more on your loved one AS a loved one and not a caregiver. This simple act can bring you closer together!

12 Take lots of pictures!

13 Write a list of daily living tasks you complete as the caregiver and the required time (e.g., bathing – 20 mins) in preparation for medical assessments

14 Complete a Green Sleeve and Personal Directive early to know your loved one's wishes. Don't forget to complete your own Green Sleeve as a caregiver

15 Encourage your loved one's independence and empower use of their abilities by allowing them to complete daily living tasks when able or with necessary supports (e.g., adaptive cutlery to safely eat by themselves)

16 Use blister packs for medications, which are available by request from the pharmacy

17 Practice self-care! Think of your caregiving abilities as a bank; if you continue withdrawing money without replenishing, eventually it will be empty

18 Participate in caregiver supports available virtually or locally (e.g., PAA care partner support groups and/or Care Partner Program)

19 Keep physically close to your loved one (e.g., holding their hand or sitting close by) and spend quality time with them often as you can

20 Remember that you're managing an extremely challenging situation and doing the best you possibly can for your loved one

Join Us September 10 & 11 across Alberta!

WHY We Walk!

This year marks our 10th anniversary of Step 'n Stride, and is our largest fundraiser of the year, accounting for over 20% of our annual budget.

Last year, we raised over $435,000 for our Parkinson's community, and hope to raise $500,000 in 2022!

We walk at Step 'n Stride to help raise awareness of Parkinson disease and Parkinson Plus Syndromes, which affects more than 1 in 500 people across Canada, and more than 10,000 Albertans.

We walk at Step 'n Stride to help raise the funds needed to deliver the programs and services our communities have come to depend on.

We walk to support the ones we love and care for.

WHAT to expect?

This September we celebrate 10 years of Step 'n Stride, and all of our events will be bigger, better and more engaging!

The theme for 10 years is Strength and Resilience, and that exemplifies our entire community!

Friendship, fresh air, and exercise will be just a few of the benefits at your Walk location. You can also expect great food and treats, entertainment, activities and games, prizes and even a few surprises!

WHO is Step 'n Stride for?

Step 'n Stride is for everybody! These are all-ages events, with activities for everyone. Registering for an event does not mean you have to come out and walk with us; we'd love to have you come and cheer us on, and enjoy the fun, fellowship and food.

Register at parkinsonassociation.ca and get started today!

WHEN to register?

The sooner you get started, the more money you will be able to raise.
Our new fundraising platform has many interactive tools to help you connect with your contacts and donors, and the more time you give yourself, the better.
Rates of diagnosis will double in the next 10 years and with your help, we will continue to meet the needs of our community.

Start your team today, and begin planning your fundraising strategy!

WHERE can I walk?

Step 'n Stride takes place in 9 locations across Alberta, but where you choose to walk for Parkinson's is up to you! We would love to see you at one of our events, but whether you and your family walk around your local park, walk your neighborhood, or even just walk the halls of your building, you'll still be walking with us, and for us!

Saturday, September 10

Calgary
South Glenmore Park
Registration: 9AM Walk: 10:30AM

Edmonton
Rundle Park ACT Centre
Registration: 9AM Walk: 10:30AM

Red Deer
The Golden Circle, 4620 - 47A Ave.
Registration: 9AM Walk: 10AM

Lethbridge
Henderson Lake Park, Kinsmen Shelter
Registration: 9AM Walk: 10AM

Lloydminster
Bud Miller Park
Registration: 9AM Walk: 10AM

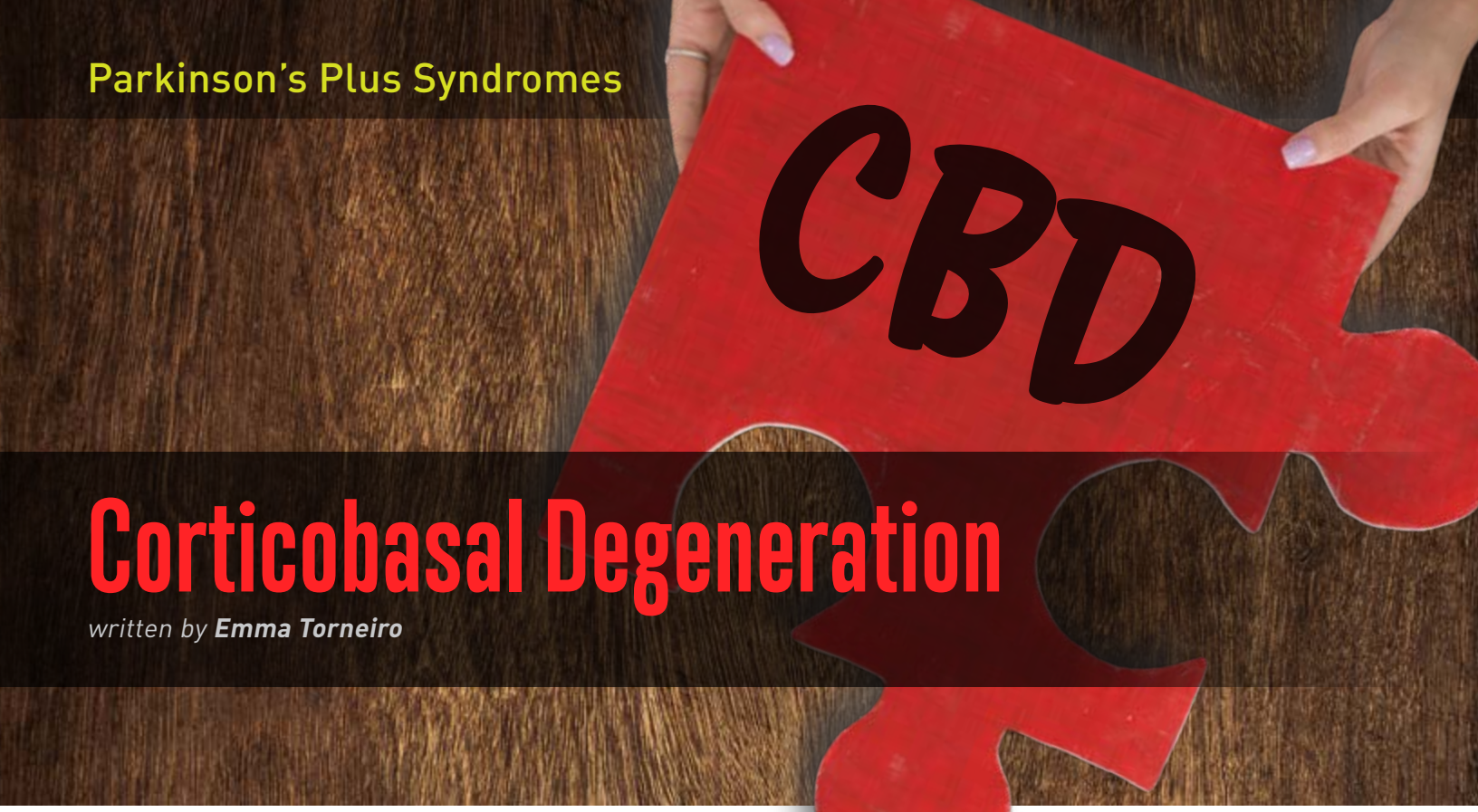
Sunday, September 11

Camrose
Grand Drive Park
Registration: 1PM Walk: 2PM

Cochrane
Mitford Park
Registration: 1PM Walk: 2PM

Grande Prairie
Muskoseepi Park, Ernie Radbourne Pavilion
Registration: 1PM Walk: 2PM

Medicine Hat
Kin Coulee Park
Registration: 1PM Walk: 2PM



Corticobasal Degeneration

written by ***Emma Torneiro***

Corticobasal Degeneration (CBD) defines the rare progressive movement disorder resulting from gradual shrinking (atrophy) and cell degeneration within two areas of the brain: the cerebral cortex and basal ganglia[1].

The cerebral cortex is responsible for our thinking, speech and sensory perception and the basal ganglia is responsible for coordinating our movements. What does this definition really mean? In CBD, the brain slowly shrinks, and the cells deep within the brain deteriorate leading to the motor, speech, and cognitive symptoms.

The cause of CBD is currently unknown; however, research has demonstrated the reason for the degeneration is connected to malfunctioning tau protein within the brain, similar to PSP[1]. The tau protein, which appears in all our brains, is primarily responsible for holding structures called microtubules together and transporting messages of movement between our brain and skeletal system. The microtubules are responsible for cell growth, movement, and cellular transport. In CBD and PSP, the tau protein clumps into knots called neurofibrillary tangles and the microtubules separate, leading to the dysfunction of the tau protein[1]. This means that clumps of tau protein are floating within the brain, leading to the brain being unable to send accurate messages for movement to the body and being unable to promote cell growth. The term CBD describes what is occurring neurologically in the brain, meaning the clumps of tau protein and cell death[2].

The term Corticobasal Syndrome (CBS) defines the visual symptoms leading to diagnosis[2]. The variations of CBD are connected to the area of the brain being affected and how the symptoms present at onset. The types of CBD include CBS[2], Frontotemporal Dementia (inability to organize thoughts or control impulse behaviours)[1], and Aphasia (speech disorder)[1]. The forms of CBD typically include partial Parkinsonian symptoms and will progress through the other symptoms, described below. The condition is similar to Parkinson disease (PD) in many aspects, but CBS includes accelerated progression and limited response to PD medications. For example, the initial symptoms of CBS present unilaterally (one sided) but rapidly progress bilaterally (two sided)[1], which differs from typical PD with unilateral symptoms throughout the disease.

The diagnostic process for CBD involves an examination of motor symptoms, cognitive symptoms, rate of progression, and brain imaging scans (e.g., MRI for brain shrinkage) to eliminate the possibility of other conditions. The diagnostic process can also include testing for speech apraxia (language forming problems), sensory functioning and memory or cognition. Due to the scans being unable to differentiate between conditions and the Parkinsonian symptoms at onset, it is common to initially receive a Parkinson diagnosis. The diagnostic process does not include examining familial medical history, as CBD is considered sporadic and is rarely connected to genetics[1].

The Facts

- The average age of onset is 50-70
- Life expectancy is 6-8 years following symptom onset
- It is a rare brain disorder accounting for 4-6% of the Parkinson's Plus population[3]

Motor Symptoms

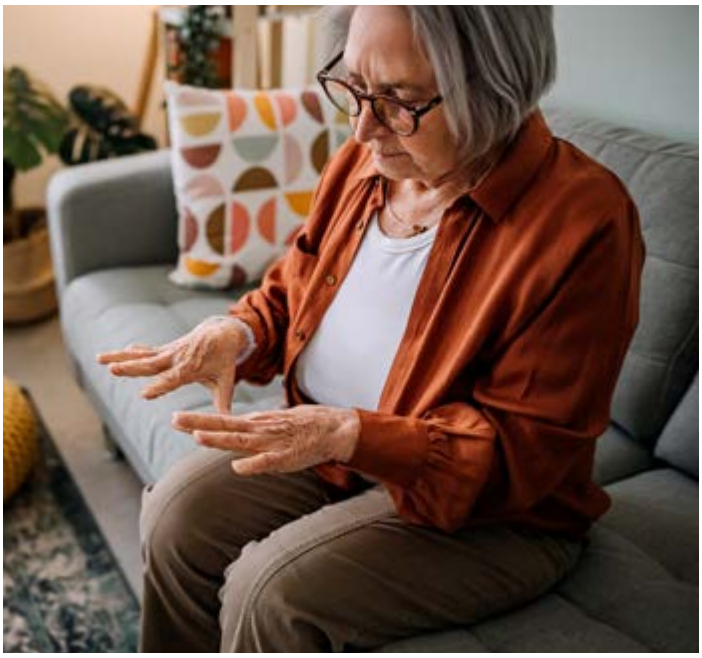
- Parkinsonian symptoms
- Apraxia (*loss of ability to perform previously known tasks*) leading to difficulties with fine motor and limb movements[1]
- Alien Limb Phenomenon (*involuntary limb movement and sensation that the limb is alienated from body*)[1]
- Arm Levitation (*involuntarily moving arm upwards*)[1]
- Difficulty controlling or directing muscle movements appropriately, specifically with face, mouth, and hands[4]
- Difficulties with coordination, balance, gait stability, and increased falls
- Ataxia (*uncoordinated movements appearing as "drunk walking"*)
- Myoclonus (*rapid, jerky, and irregular movements in limbs or trunk*)[1]
- Dystonia, presenting as fixed abnormal posture or dystonia in limbs (*ex. clenched fists*)[5]
- Abnormal eye movements or uncontrolled blinking[6]
- Freezing of gait

Speech Symptoms

- Aphasia (*language disorder*)
- Impacts on ability to verbally communicate due to difficulties cognitively understanding language, expressing oneself, recollection of words and producing words
- Speech apraxia
- Dysarthria (*difficulty with speech*)
- Slurred speech
- Dysphagia (*difficulty swallowing*)
- Hypophonia *(soft speech)*
- Halting speech

Cognitive Symptoms

- Frontotemporal Dementia, which is characterized by the inability to control impulses, difficulty with executive functioning and personality changes[1]
- Difficulty controlling behavioural inhibitions
- Difficulties with cognitive processing (*multi-tasking and planning ahead*)
- Cortical Sensory Loss (*decrease in sensory abilities, inability to interpret various objects through tactile sense, and inability to differentiate spatial surroundings)*[1]



Treatment Options

There is no specific medication to treat CBD, slow the progression or manage the cognitive changes of the disease, therefore the treatments target daily management of symptoms. Due to the presence of Parkinsonian symptoms, neurologists may initially prescribe a higher dose of the common Parkinson medication, Levodopa Carbidopa, for management of the motor symptoms. However, the responsiveness to Levodopa Carbidopa for CBD is generally minimal or creates increased side effects leading to discussions with the healthcare team about cessation of medication. The secondary Parkinson medication that may be prescribed in smaller doses is Amantadine to manage freezing of gait[1]. The healthcare team may also prescribe additional medications to manage the treatable conditions (e.g., sleep issues, myoclonus, dystonia).

The main treatment options for CBD focus on using therapies for management of symptoms and improvements to quality of life. The recommended therapies include physiotherapy for mobility, occupational therapy for assessment of mobility aids, and speech therapy for challenges with speech, swallowing, and communication. The use of a dietitian is beneficial for help with proper nutrition and finding easy to swallow diets to decrease risk of aspiration. Finally, psychologist or social workers can provide support for the non-motor symptoms (depression, anxiety, apathy) of the diagnosis.

Resources

1 *Golbe, L.I. (2019, July). CBD: Some Answers. CurePSP. https://www.psp.org/wp-content/uploads/2021/04/2019-MSA-SOME-ANSWERS-BROCH_web.pdf*

2 *Armstrong, M. (2020, March 26). AFTD Webinar: Corticobasal Syndrome & Corticobasal Degeneration, Basics & What You Need to Know [Video]. TheAFTD Youtube. https://youtu.be/fncGNT88YAw*

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6 *Corticobasal degeneration (corticobasal syndrome). (2022, February 22). Mayo Clinic. Retrieved March 2022 from https://www.mayoclinic.org/diseases-conditions/corticobasal-degeneration/symptoms-causes/syc-20354767*

There are over 15,000 people in Alberta living with Parkinson disease and Parkinson's Plus Syndromes .

Your gift of $100 can provide 2 hours of direct support for an individual or family affected by PD and PD+.

HELP MAKE A DIFFERENCE

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September 10 & 11

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