

# Parkinson PULSE

Connecting people living with Parkinson disease in Alberta



## ***Cognitive & Psychological Changes in Parkinson's***





*Parkinson Association of Alberta is the voice of Albertans and their families living with Parkinson disease. Our purpose is to ease the burden through advocacy, education, client services and find a cure through research.*

We welcome your comments, suggestions and questions. Email us at [communications@parkinsonassociation.ca](mailto: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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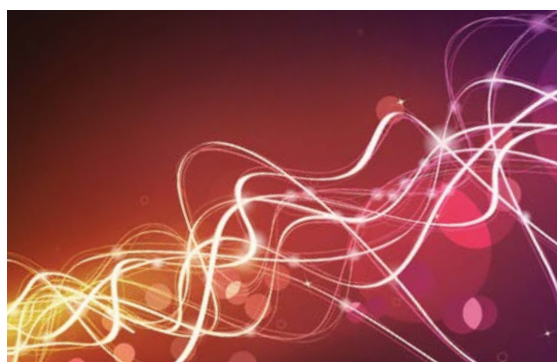
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Fall 2021

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Happy Fall everyone. In this edition of Pulse, it's my honour to be able to share a story from one of our clients in place of my usual note. Before I get into that, I want to take a moment to express my sincere gratitude for your support this summer. Whether through fundraising, calls and emails, chats in the park, or the myriad of other ways we've been able to connect, I am just so warmed by the commitment of this community. Thank you!

As an organization, we hear so many incredible stories of hope and resiliency and Cathy's is one. I am so grateful I got to spend some time with her to try to capture her experience and honour her journey. With so many variables at play, Parkinson disease is extremely difficult to diagnose. Parkinson's Plus Syndromes even more so. We are grateful for our medical community who work diligently and tirelessly to help individuals and families navigate the challenges of Parkinson disease and Parkinson's Plus Syndromes. Thank you Cathy, for your courage and inspiration and for sharing it with us.

Lana Tordoff,  
Executive Director

## Cathy's Story

Written By: **Cathy Richot** and **Lana Tordoff**

**"It's not always simple, black and white. Yes, we have Parkinson's, but it's not that simple. Not that cut and dried. In hindsight, I see signs and symptoms that I believe should have caused a medical professional to suspect it wasn't just Parkinson's."**

Cathy was in her mid-40's when she began experiencing weakness. It wasn't more explainable than that really but as a busy active wife and mother with a demanding career, she knew there was something wrong. Cathy compared herself to her much older colleagues and realized the natural aging process seemed to be hitting her harder than it should. When she started to stumble, drop things, and experience dizzy spells, she began to push her doctor for answers.

Following an ECG and a battery of other tests, the diagnosis was stress. But Cathy felt she knew her body better than to dismiss her symptoms and continued to press for answers. Because both her father and grandmother were diagnosed with Parkinson's, she suspected this was also something that should be considered. Upon being referred to a neurologist and undergoing genetic testing, it was determined that whatever was going on with Cathy couldn't be explained by inherited Parkinson disease. Yet, two years after the symptoms began, in 2015, Cathy was diagnosed with Young Onset Parkinson Disease (YOPD).

With a deep need to understand what she was facing, she reached out to the Parkinson Association of Alberta (PAA). What now? She was uncertain about sharing this diagnosis with her family, friends, or employer. Would she have to give up her career or participating in the social and physical activities she so enjoyed? Cathy would come to find a community of support with PAA where she was able to contribute and find meaning, as she moved forward in her journey.

Cathy eventually became a leader and champion for the PAA support group in Parkland County. She recalls an occasion where she happened to be the first to arrive for setup and noticed a couple standing in the reception area. After some quick organizing, something in her heart told her she had to go speak with that couple, finding out that they were recent transplants from the Yukon and were at the centre in search for community supports. It was an amazing "coincidence" that they arrived at the same time



as the Parkinson's games afternoon, as it turned out the gentleman had been diagnosed with Parkinson's and dismissed in quick succession by a neurologist visiting the area. They had so many unanswered questions and had never met anyone else with Parkinson's before. Cathy and her husband continue to enjoy a close friendship with the couple many years later.

Although Cathy initially experienced some relief through use of Parkinson's medications her cognition began to decline, and she realized it was time to leave her job. Her symptoms appeared to be advancing more rapidly than she knew to be the norm in Parkinson's patients. Her physiotherapist added to the concern when she noted that "weakness" wasn't typically a symptom of Parkinson's.

As a life-long learner, Cathy became even more committed to finding answers. Her diagnosis of YOPD and the rapid progression of symptoms simply didn't seem to match. Granted, Parkinson's looks (and is paced) so differently from person to person that it's difficult to pinpoint when and how it will progress. But Cathy was determined not to give up. She ordered every book and sought every educational opportunity available. She also found that her involvement in the Parkinson's community and resulting opportunities to hear other people's experiences were helpful in finding direction.

One of Cathy's favorite activities with PAA was a singing group at Edmonton's Buchanan Centre. As a result of financial constraints, this program ended but the interest remained. Cathy banded together a contingent of regulars who all contributed to bring the program to Parkland with a pianist and a Speech Therapist. Ever resourceful, Cathy entered a radio contest "The Helping Grand", on 96.3 The Breeze, where folks could nominate someone to receive \$1,000. They won! And the group carried on successfully at low cost to participants.

Cathy found additional enjoyment through a games group she established. Their support group wanted to spend time together between meetings and this seemed like a fun way to connect. Before long, she found that some people's partners were not very interested in playing games and so started another group where she showed folks the many brain teasers one could spend time with on their own.

**"I lose motivation to do some things, I get exhausted pretty easily, but if I can help somebody I do it, I will push through because it is so rewarding to help!"**



Cathy, with her husband Roger

With a disease that takes control little by little over time, now with daily changes, Cathy explains that doing for others is a way to have meaning in your life and a sense of control where you can find it.

Cathy's diagnosis changed to Multiple System Atrophy (MSA), a Parkinson's Plus Syndrome, in October of 2020 as a result of rapid progression of symptoms. More testing was done to help pinpoint what systems were being affected and how much medication was helping. Four to five people in 100,000 receive this diagnosis every year in Canada as compared to one in 500 with PD. The life expectancy changes from a normal adult range in Parkinson's to an average of 7-10 years after symptom onset.

**"PD is a tough challenge, and I would not wish the disease on anyone. In this battle with MSA, my greatest asset is my faith. This is where I find joy and victory!"**

Cathy is considered palliative and lives life today in slow motion. She describes routine tasks as taking a long time and a lot of energy. She is thankful that she could cut

# Cathy's Story

down on some of her medication and her side effects, such as the cognition problems and dyskinesia have gone away. Even though her symptoms get a bit worse daily she continues to find joy; her faith is strong, and she takes time to look for the silver linings!



Despite following all public health orders and recommendations, Cathy and her husband contracted Covid-19 in December of 2020. Thankfully, the medical community was very thorough, and their church family left many meals and treats on their front porch! In February 2021, after receiving her palliative diagnosis and with permission from AHS hospice care, Cathy has received regular visits from a myriad of "cousins and siblings" as well as her kids, one of whom introduced the family to a new grandchild on Valentine's Day! "My loved ones are my family."

Cathy could feel frustrated and bitter about her experience with the healthcare system and the time it took to receive an accurate diagnosis; instead, she shares the following:

**"Everything happens for a reason. Even if I had to go through this, I didn't do it alone. Maybe I had to learn things this way. Would I have these friends or gotten involved in this way? I appreciate the people I met and the experiences I have had! I've grown so much during this journey! And it was kind of hard when my diagnosis changed from YOPD to MSA. It was back to where do I fit in? And the "No, not MS, but MSA!" So much to learn, so much to teach! Lol"**

She wants to encourage medical professionals to listen with open ears and empathy to their patients. For individuals looking for answers, she says to "trust and educate yourself – when you hear the truth and it resonates with you, there is a relief and acceptance. Listen to people – don't be blinded – but listen to all the advice you can get even if it might not work for you, because later it might come in handy even for someone else."

Cathy has seen people with Parkinson disease and Parkinson's Plus Syndromes sink into depression and even take their own lives. Family heartbreak is common. She found that the instinct to withdraw and feelings of being alone and embarrassed are not helpful, and that organizations like Parkinson Association of Alberta can provide a safe place where shared experiences mean a real lack of judgement. "100% of the people are wonderful."

**"Always have hope and faith – this isn't about me, it's about us. It's a journey. We all have different journeys, and they take us to different places. Connect with people who are on the journey with you and just love them. Why not? Then every day can be a blessing to you and to others. You are valuable, important, worthy, needed, wanted, loved!"**

Cathy is 52 years old.

## JOIN OUR CIRCLE OF HELP



### GIVE A GIFT

Text **HOPE** to 80100 to donate \$10 or \$25 to Parkinson Association of Alberta



### SHARE ON SOCIAL MEDIA

Tag us and use the #circleofhelp



### BECOME A MEMBER

Join our safe and caring community of support.



The challenges and successes you share help others. It is for you, and because of you, that we learn and grow as a staff and as a part of the Parkinson's community. The conversations you have with us, the insights you share and the feedback you provide us helps create the path forward...together.

We would love to receive more feedback from you on our magazines – be it the issue as a whole or a specific article. Did something you read help you? Did you not care for a particular article? (It's ok, honest, we want to know!) It is always our sincere hope that each issue will offer readers some level of insight or knowledge, AND start conversations be it at home or with peers! Below we share some feedback we received for our Summer 2021 issue "Non-Motor Symptoms of Parkinson Disease – Greatest Hits Volume 1" issue.

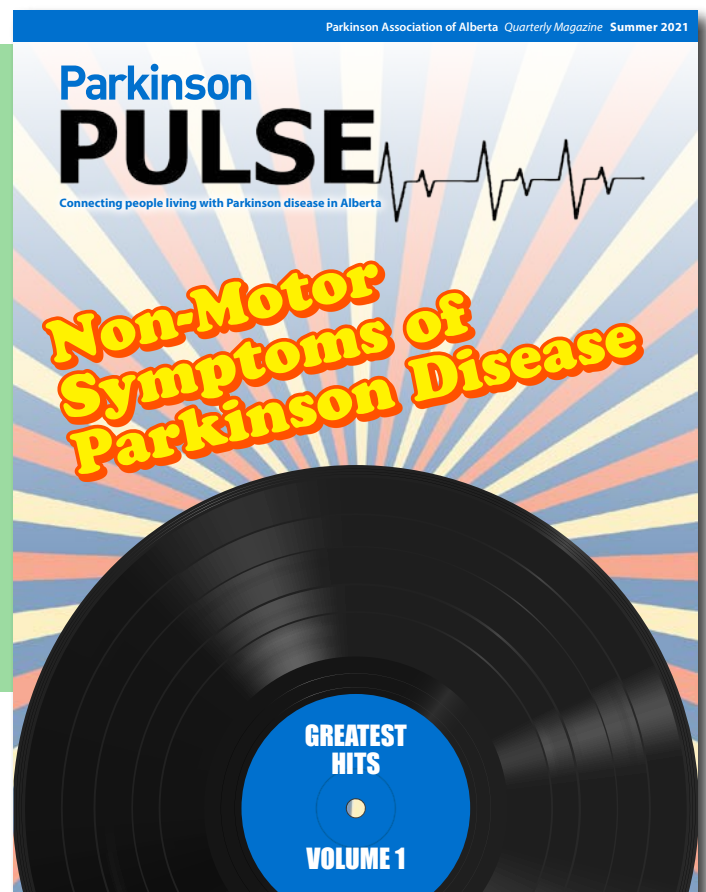
***This was a really great issue.  
Very helpful in explaining the different  
symptoms that happen. I thought the  
music choices were clever and well done.  
We look forward to Volume 2.***

*-The Johnsons*

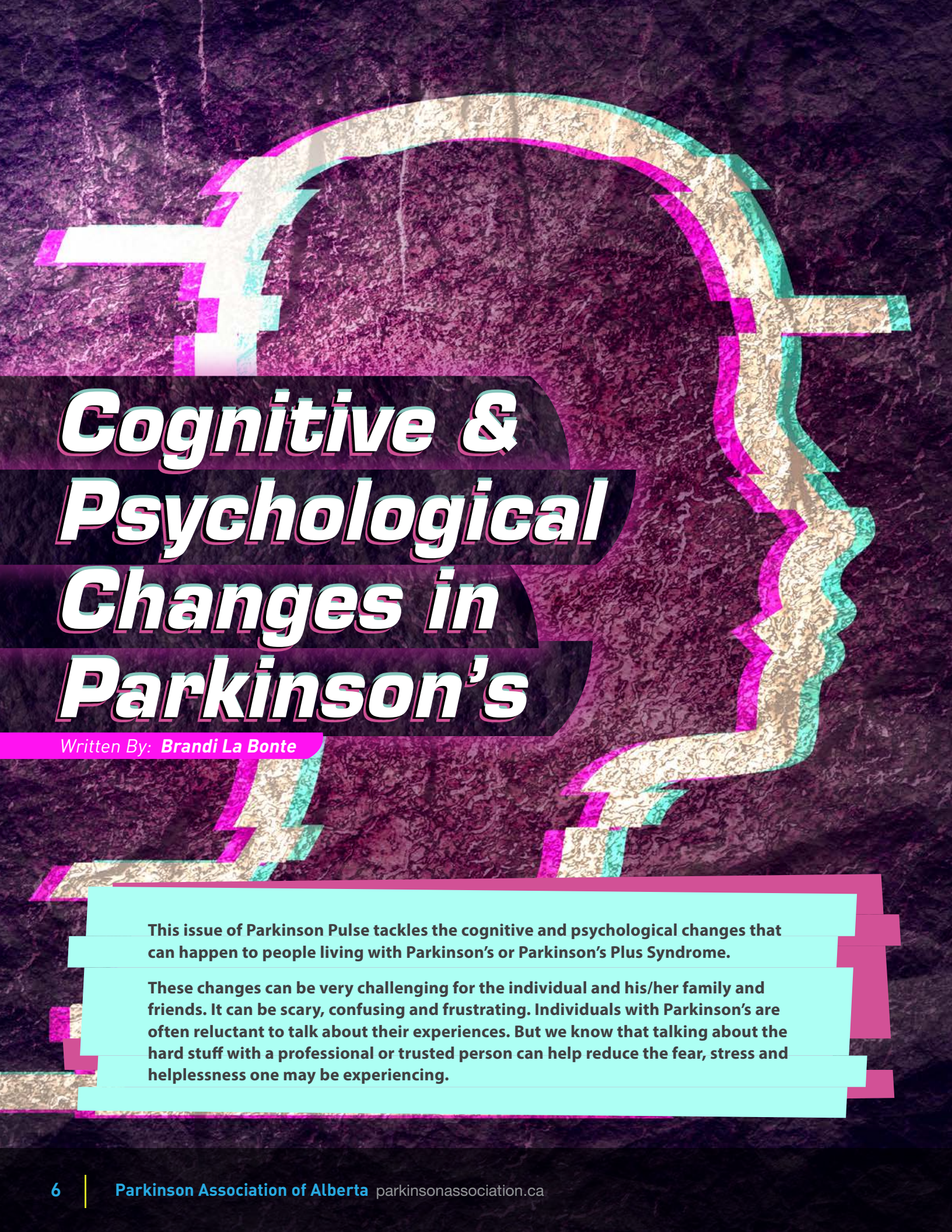
***Congrats to Brandi and the Team for  
producing a most excellent summer issue  
of Pulse. The articles were instructive and  
well presented and I really enjoyed the  
music theme. Some of my favorite tunes  
here! You have my vote for Volume 2!***

*-Jim Archibald*

Your feedback, comments, and insights are ALWAYS welcome! In fact, we would like to highlight them (as we've done here) in future magazines. Share your feedback with your Client Services Coordinator, **call us toll-free** at 1-800-561-1911, or **email us** at [communications@parkinsonassociation.ca](mailto:communications@parkinsonassociation.ca).







# ***Cognitive & Psychological Changes in Parkinson's***

Written By: **Brandi La Bonte**

This issue of Parkinson Pulse tackles the cognitive and psychological changes that can happen to people living with Parkinson's or Parkinson's Plus Syndrome.

These changes can be very challenging for the individual and his/her family and friends. It can be scary, confusing and frustrating. Individuals with Parkinson's are often reluctant to talk about their experiences. But we know that talking about the hard stuff with a professional or trusted person can help reduce the fear, stress and helplessness one may be experiencing.



There is a lot of stigma and fear when it comes to cognitive and psychological issues, which is why, unfortunately, many people won't talk about it – even with their doctors. They may not want to think about or consider what is happening or what the future might hold. And talking about these changes can be daunting for both the person with Parkinson's AND their loved one(s) as many people fear how the other will react. This is understandable, relatable even however this avoidance can make things much harder for you, and your loved one as these types of symptoms begin or progress.

Like many non-motor symptoms in Parkinson disease, not everyone with Parkinson's will experience cognitive or psychological changes or will experience them to varying degrees. The impact of the cognitive and psychological changes that can happen in Parkinson's can often be overlooked because they are not always easy to see, especially at first. The changes start small, subtle even. A momentary pause to find a word or a temporary lapse in judgement. We chalk it up to getting older, stress or a bad day. But these changes



can be attributed to Parkinson disease – either the disease itself, or as a result of the medications one is taking to help control Parkinson's symptoms.

In this edition of Pulse, we talk about the main cognitive and psychological issues people may experience cognitive impairment, impulsive/compulsive behaviors, hallucinations and delusions, and Parkinson disease dementia. These issues can be intimidating or even frightening to think about, let alone talk about. I'm proud of the approach Brienne, Declan and Emma took in researching and writing these thoughtful and informative pieces.



Does having the knowledge or talking about it necessarily mean things can be "fixed"? No, and that is hard; but it does mean that we have the support and knowledge to choose our own paths and plan for whatever the future may hold. The hope and power to prepare for what may or will come. There is independence, strength and bravery in that.

Being brave doesn't mean you aren't afraid. It is the opposite actually. Being brave is the ability to move forward, make decisions and take actions in spite of fear.



# IMPULSE CONTROL DISORDERS in Parkinson Disease

Written By: **Brienne Leclaire**

Impulse Control Disorders are a group of excessive and/or harmful urges and behaviors that may occur in people with Parkinson disease. They are characterized by persistent thoughts or uncontrollable urges to do things.<sup>1</sup> The most common impulse control disorders seen in Parkinson disease are:

## » **Pathological Gambling**

more likely to be experienced by men with Parkinson's.



## » **Hypersexuality**

new or dangerous sexual activity, inappropriate touching or comments to others, sexual activity outside of current relationship, new or increased use of pornographic material.



## » **Excessive Spending/ Shopping & Other Manifestations**

large changes in spending or shopping habits (eg purchasing clothing items one never wears or numerous items – 6 toasters – that one doesn't use), hoarding.



## » **Binge-Eating/ Over-Eating**

consuming large portions of food, often quickly, without being able to stop and to the point of being uncomfortably full or making oneself ill.





# IMPULSE Control Disorders in Parkinson Disease

Impulse control disorders are behavioral disturbances in which a person fails to resist the drive to behave in ways that result in distress or impaired judgement.<sup>2</sup> This behaviour can have significant impacts on people's financial, social, emotional, and physical well being. Impulse control issues in Parkinson disease are predominately caused by dopamine agonists. About one in six people taking dopamine agonists will experience impulse control disorders to differing degrees of severity. Some people experience mild impulse control issues for example hyper focusing on eating sweets. Others experience more severe impulse control issues like chronic gambling.

## WARNING SIGNS

Warning signs can include things like rapid weight gain, overspending, increased gambling, inappropriate sexual behaviour, obsession or compulsions around food, sex, or gambling. New or worsening drinking or drug use or risky behaviours are other common signs. Other symptoms of impulse control issues to watch for include hiding or sneaking things/money, sudden changes in behaviour routine, changes in sleeping habits, being defensive or lying about behaviours, avoiding others. If you suspect an impulse control issue keep track of any new or changing behaviours and any concerns. As well, as keep track of any medication changes or in how the medication is being taken. These can be valuable in relaying the changes, concerns, and behaviour to health professionals.

## HOW IT'S TREATED

Impulse control disorders in Parkinson's are typically treated by stopping or lowering the medication causing the issues. Medications might be changed to remove or lower the dopamine agonist to try to stop impulse control issues. While subsequently managing Parkinson's symptoms. The second part to treating impulse control issues is removing or limiting access to participate in the behaviour. Restricting these behaviours and diminishing access to them help control the damage done by these impulses.

## References

<sup>1</sup> International Parkinson and Movement Disorder Society. "Impulse Control Disorders in Parkinson's Disease." 2018. <https://www.movementdisorders.org/MDS/Resources/Patient-Education/Impulse-Control-Disorders-in-Parkinsons-Disease.htm>

<sup>2</sup> Pontone G. "Impulse Control Disorders & Parkinson's." APDA, Nov 2018, <https://www.apdaparkinson.org/what-is-parkinsons/symptoms/impulse-control-disorders/#:~:text=Impulse%20control%20disorders%20%28ICDs%29%20are%20behavioral%20disturbances%20in.>



For example, if gambling is the issue restricting access to money, bank, and credit cards, restricting access to online sites, and removing valuables can help remove access to participating in the behaviour as medication is sorted out. This also helps protect them and those around them from serious effects of the behaviour. Counselling is the third part of treating impulse control issue. Impulse control issues can have other long term emotional, physical, and financial effects for the person with Parkinson's and their loved ones. Counselling can help address these issues, set goals, and repair relationships impacted by impulse control issues.

## WHO TO CONTACT FOR HELP?

If you suspect you or your loved one is experiencing impulse control issues, contact your doctor. Keep a log of medication, medication changes, physical or behavioural changes and any other notable events, with times and dates to help the doctor get the best understanding of the situation. Your family doctor and neurologist will be a key part of handling impulse control issues.

Impulse control issues can lead to distress in not only the person with Parkinson's but the family as well. Counselling can help address issues, stresses, repair relationships and provide strategies to overcome issues arising from impulse control issues.



# What's Real?

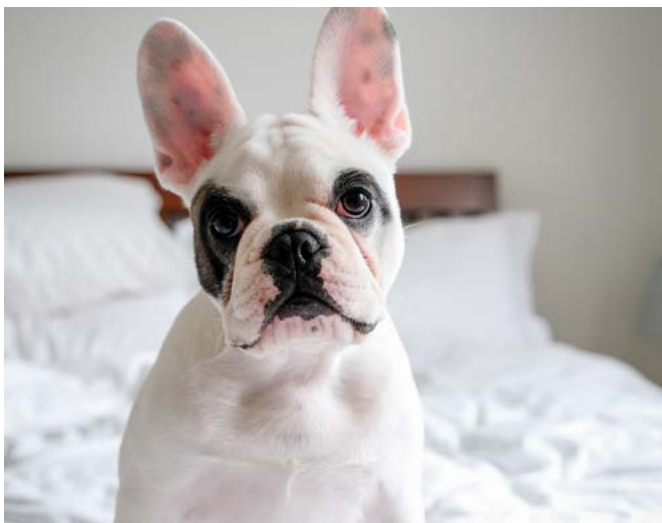
## Understanding Parkinson's Psychosis

Written By: *Emma Torniero*

Have you or a loved one with Parkinson disease seen, heard, or felt symptoms that no one else noticed? Maybe it was a squirrel running up the tree in the backyard, a small dog at the edge of the bed at night, the belief that someone is “out to get you” or you were being cheated on. These symptoms are categorized as hallucinations and/or delusions; and are collectively referred to as Parkinson's psychosis. These sneaky deceptions played by the brain involve our senses and can often create confusion between reality and perceptions of items that are not present. The symptoms of Parkinson's psychosis impact 20-40% of people with Parkinson's throughout their journey with the disease.<sup>1</sup> As the disease progresses, the likelihood of developing hallucinations and delusions increases.

We understand the conversation around hallucinations and delusions can be difficult and frightening but it's important not to shy away from the conversation. This article will differentiate between hallucinations and delusions, discuss the why of Parkinson's psychosis, offer treatment options.





## Hallucinations

Remember that squirrel running up the tree or the small dog at the edge of the bed that no one else noticed? Hallucinations are best described as perceiving something that isn't really there. They are more common than delusions and typically involve one or more of one's five senses with visual hallucinations being the most commonly reported. The person experiencing the hallucination may see (ie: a person sitting on the couch or a dog at the foot of the bed) or hear (ie: a radio playing or a person talking) something that no one else can.

Most hallucinatory experiences are short in duration (often less than 5 minutes) and are typically not harmful or scary for the person experiencing them. During the hallucination, the person maintains visual and spatial recognition, meaning they're alert, aware of their surroundings and can often remember the hallucination. Hallucinations can often be more frightening for the care partners and loved ones to hear their loved one speak about things they cannot see or hear themselves.

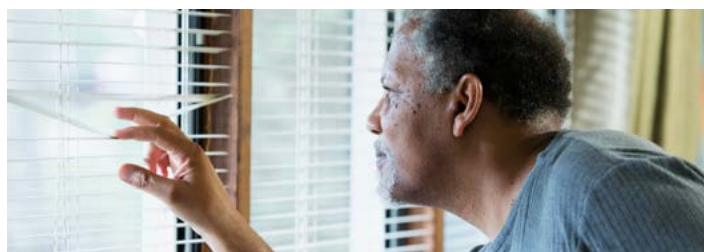
The hallucinations can become more threatening and problematic for the person with Parkinson's. Therefore, it is important to share your experience with hallucinations with your medical team to ensure they are tracked and managed if they become more problematic. The other less common types of hallucinations are auditory (sound), olfactory (smell), tactile (touch), and gustatory (taste).

## Delusions

Remember the belief that someone is "out to get you" or you were being cheated on? These false, fixed beliefs are known as delusions. Delusions are best described as a belief that isn't based in reality. As a result, the belief lacks sensory or objective evidence for those around the person experiencing a delusion. A person experiencing a delusional episode will often appear confused and experience a change in concentration and awareness, as well as becoming solely focused on the false belief.

The most common types of delusions people with Parkinson's Psychosis may experience are:

- » **Jealousy or possessiveness** – wherein they believe that someone has been unfaithful or disloyal to them, which can result in paranoid and suspicious behaviors towards the person they feel "wronged" them.
- » **Persecutory** – wherein they believe that someone is "out to get them" or harm them in some way, which can result in social withdrawal or defiant behaviors (fight or flight).
- » **Somatic** – wherein they believe they have an injury or medical issues, which can result in increased anxiety.



Delusions are more complex to treat than hallucinations and can lead to aggressive behaviors (arguments or even physical altercations) which require more immediate action and/or intervention from outside supports. The delusions can begin slowly as confusion at night and develop into complete paranoia towards spouse, family, and support system. Fortunately, delusions are less common than hallucinations. The onset of delusions can signify a greater impact of disease on cognition and ability to care for themselves. It is important to speak with your medical team as early as possible if you or your loved one is experiencing delusions.



# What's Real? - Understanding Parkinson's Psychosis



## Causes of Hallucinations & Delusions

One of the main questions associated with hallucinations and delusions is: why do they happen? There are many risk factors that can influence the onset of Parkinson's psychosis symptoms, including the level of dopamine from medications, sleep disorders, age, disease progression, stress, cognitive impairments and the non-motor symptoms of depression and anxiety. The main causes of hallucinations and delusions are chemical changes within the brain. The changes are connected to high levels of dopamine within the brain, as a side effect of medication. As we know, the symptoms of Parkinson disease develop as dopamine producing cells within the brain begin to die off. The Parkinson's medications mimic or replace the lacking dopamine to help manage the motor symptoms. As the disease progresses, the level of medication required typically increases. In effect, the medication inadvertently creates chemical changes in the brain, which may cause hallucinations and delusions. This does not mean that you or your loved one should completely stop the Parkinson's medications to eliminate the hallucinations and/or delusions. However, it may mean working closely with a medical team to narrow the cause and adjust your medication schedule. Always remember – medications are an essential treatment option in managing Parkinson disease!

The other contributing factors to experiencing hallucinations and delusions are dementia and delirium. For individuals experiencing cognitive impairments or diagnosed with dementia, the risk of hallucination increases due to chemical changes within the brain that cannot be managed by medication. The final factor of delirium is typically connected to an infection or other medical condition and can be managed by seeking treatment for condition or eliminating medication causing delirium. It can be difficult to narrow down the exact cause of the hallucinations or delusions, but it is important to keep your medical team informed and connected to manage the symptoms of Parkinson's psychosis.

## Treatments

Treatment options to manage hallucinations and delusions primarily involve the use of prescribed antipsychotic medications. The antipsychotic medications balance the chemical levels in the brain, resulting in a reduction or management of hallucinations. One of the medications available is Pimavanserin, an atypical antipsychotic medication that was approved specifically for the treatment Parkinson's psychosis.



The medication decreases hallucinations without affecting motor symptoms or blocking dopamine within the brain. However, it cannot be used for individuals diagnosed with dementia. The hallucinations and delusions may be reduced or managed by adjusting the dosage and schedule of current Parkinson's medications with your health care team.

Remember – it is important to speak with your medical team regarding any medication changes or questions about medications.

## References

<sup>1</sup> Parkinson Foundation (2021). "Hallucinations/Delusions."

<https://www.parkinson.org/Understanding-Parkinsons/Symptoms/Non-Movement-Symptoms/Hallucinations-Delusions>

# 10 Tips

## for Care Partners Whose Loved Ones are Experiencing Hallucinations or Delusions

Written By: *Emma Torniero*



- 1** When your loved one is experiencing a hallucination or delusion, try to remain calm and avoid arguing with them. It feels extremely real to the person experiencing it. If you feel the need to explain that you can't see what they see, do so in a non-confrontational manner, such as saying "I know you see something frightening over there, but I don't see it."
- 2** Acknowledge your loved one's experience/thoughts and validate their experience to reassure safety.
- 3** Try to distract your loved one by shifting their attention to something they enjoy doing. This could be putting on their favorite music or TV show, going for a walk, or engaging in one of their hobbies.
- 4** Try to reduce stressors or triggers - change your loved one's surroundings by removing objects which may be causing the hallucination. For example, a coat rack might look like a person standing in the room.
- 5** In an effort to reduce hallucinations, ensure sufficient lighting in darker areas. For example, add a night light in bedroom or opening the blinds/curtains to let in the sunshine and natural light.
- 6** Track the symptoms, potential triggers and behaviours associated with Parkinson's psychosis.
- 7** Share the type, frequency, and behavioral details of Parkinson's psychosis episodes with your loved one's medical team – the earlier the better.
- 8** In partnership with the medical team, try to rule out possible causes for psychosis such as infection, sleep disorders or vision issues as well as adjusting Parkinson's medications or adding antipsychotic medications to the regimen to manage psychosis symptoms.
- 9** In partnership with your medical team, discuss the effects of non-motor symptoms on behaviour and ensure non-motor symptoms are managed through therapy and/or medications.
- 10** Connect with other Care Partners! Always remember you're not alone in managing the challenges associated with Parkinson's psychosis. There are other Care Partners across the province that understand what you're going through and can provide peer support.

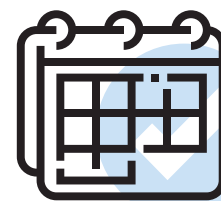


## WHAT'S NEW?

### Important Dates to Remember

All PAA Offices will be closed on the following dates:

- **October 11** (Thanksgiving)
- **October 28 & 29** (Staff Planning Meetings)
- **November 11** (Remembrance Day)
- **December 24 – January 2** (Winter Break).



**PUT THIS ON  
YOUR CALENDAR!**

**Saturday, November 20th:** We are working with partners and friends to once again bring education and inspiration in a virtual Hope Conference. Stay tuned...

### Support Group News

Our provincial Under 55 Support Group has been re-named and is now our **Young Onset Support Group**.

While we realize many of our clients were diagnosed as "Young Onset" initially, this group is specifically for those people diagnosed with Young Onset Parkinson's (YOPD) and their care partners who are currently within their first 10 years of diagnosis.

This provincial support group is aimed exclusively for individuals and their loved ones navigating a PD diagnosis at a younger age. Discussion topics include finding a work-life balance, maintaining a social life with YOPD, talking to young children/teens about PD and the unique challenges associated with YOPD.



This virtual (ZOOM) group is open to anyone in the province and is offered in the evening to accommodate busy daytime/work schedules.

*Not sure if the group is right for you? Contact your local Client Services Coordinator or call us toll-free 1-800-561-1911 for more information or to register.*

Please see page 15 for more details!

### New Partnership!



Parkinson Association of Alberta is pleased to be collaborating with the Occupational Therapy staff and students

from University of Alberta's Faculty of Rehabilitation Medicine. Our aim is to create in-person and virtual opportunities for people with Parkinson's and their loved ones to help maintain safety and independence through Occupational Therapy. More details will be available in the new year but please connect with us to add your name to the "I'm Interested" list or to learn more.



We'd like to take this opportunity to thank and shine a spotlight on the **Alberta Retired Teachers Charitable Foundation**. Over the past few years ARTCF has provided ongoing funding for our tele-support programming. This year their **\$25,000** support has enabled us to expand and grow our provincial support options to include SEVEN support groups and reach more people!

Thank you **Alberta Retired Teachers Charitable Foundation** for helping us ensure that no matter WHERE individuals and families live in this province, they have access to the vital support and services they need to live well with Parkinson disease and Parkinson's Plus Syndromes.

**REMINDER:** To register please call toll-free **1-800-561-1911** or, talk to or email your Client Services Coordinator. Advance registration is **required** for each and every Support Group. 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.**

PROVINCIAL (ZOOM/CALL-IN ONLY) 1-800-561-1911	
1st Tuesday – <b>DBS/Duodopa</b>	1:00PM
1st Thursday – <b>Widows/Widowers</b>	9:30AM
2nd Monday – <b>Care Partners AM (new group)</b>	9:30AM
2nd Wednesday – <b>Young Onset (Under 55)</b>	7:00PM
3rd Thursday – <b>General Parkinson's</b>	10:00AM
3rd Thursday – <b>Care Partners PM (new group)</b>	1:30PM
3rd Saturday – <b>Parkinson's Plus</b>	12:00PM
CALGARY REGION 403-243-9901	
AIRDRIE	
3rd Tuesday	10:00AM
CALGARY	
1st Tuesday – <b>Northwest</b>	10:00AM
1st Thursday – <b>Northeast</b>	10:00AM
3rd Tuesday – <b>Care Partners</b>	1:30PM
3rd Thursday – <b>Southwest</b>	10:00AM
4th Tuesday – <b>Southeast</b>	10:00AM
4th Tuesday – <b>Central</b>	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 – <b>South</b>	1:00PM
1st Thursday – <b>Care Partners</b>	10:00AM
3rd Wednesday – <b>Central</b>	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	
3rd Thursday	10:00AM
WHITECOURT	
3rd Thursday	10:00AM
GRANDE PRAIRIE REGION 780-882-6640	
GRANDE PRAIRIE	
2nd Wednesday (new time)	1:00PM
LETHBRIDGE & MEDICINE HAT REGION 403-317-7710 403-526-5521	
LETHBRIDGE	
3rd Thursday	2:00PM
MEDICINE HAT	
4th Thursday	1:30PM
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 (new day & time)	10:30AM
RED DEER REGION 403-346-4463	
CASTOR	
3rd Tuesday (new day & time)	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	
3rd Thursday	10:00AM



# Mild Cognitive Impairment & Parkinson Disease

*Written By:  
Declan Beddow*

**What is mild cognitive impairment and how does it affect the day to day lives of people with Parkinson's? Mild cognitive impairment (MCI), as the name suggests, is a mild but noticeable decline in an individual's cognition, mainly in the areas of attention, memory, visuospatial function, and executive function. Mild cognitive impairment is present in 15 – 20% of individuals with Parkinson disease at diagnosis, and about 30 – 40% of people with Parkinson's currently experience mild cognitive impairment. Below we will detail each area of cognitive impairment with real life examples, as well as discussing what can be done to improve cognition in people with Parkinson disease.**



## Impaired Attention

As the name suggests impaired attention has to do with difficulties focusing and concentrating. Individuals with impaired attention may encounter difficulties when focusing on one task for long periods of time, multi-tasking, or making mental calculations. They may find that their attention wanders more easily or that things that once came easily require more mental effort now. Day to day activities like cleaning the house, preparing a meal, reading a book, or playing a card game all require a level of attention that could be impacted by impaired attention. It is important to note that these tasks do not become impossible, they may just require more effort to complete.

## Deficits in Memory

Deficits in memory are categorized by changes to how easily a person can recall, learn, and retain information or experiences. Most people with Parkinson's who experience deficits in memory are still creating new memories, they just have a difficulty retrieving those memories when needed. You can think of your brain like a computer or filing cabinet with many different files (memories) saved in it. Those files are in your possession, but it may be difficult to find the file you are looking for in the moment. Someone experiencing deficits in memory might have difficulty remembering the details of their previous day, or have trouble learning how to perform a new task.

## Impaired Visuospatial Function

Visuospatial function is the ability to analyze and understand the objects in our environment, how they relate to one another, and where they are in our space. When visuospatial function is impaired, it can affect depth perception, sense of direction, and the ability to visualize objects clearly in your mind (mental imagery). This may affect an individual's ability to button a shirt, assemble furniture (or other products that require assembly), or navigate around obstacles in their way. It is also important to consider that driving can be significantly impacted and may be unsafe if you are experiencing impaired visuospatial function.



## Impaired Executive Function

Executive function is the ability to make complex plans, focus our attention, multi-task, problem solve, and use critical thinking and reasoning when making decisions. Simply put it is our ability to think and make judgements. Impaired executive function can impact many areas of daily life such as, paying bills, planning trips, playing sports, working and/ or participating in conversations.



# Mild Cognitive Impairment and Parkinson Disease

## What can be done to help with cognitive function in Parkinson's?

As of right now there are no effective medications for improving cognition in people with Parkinson's who experience mild cognitive impairment. This means that the best way to improve mild cognitive impairment is through lifestyle changes and the treatment of other symptoms which can worsen MCI.



### Exercise

We all know that exercise is an important part of symptom management for people with PD, but it isn't just beneficial for motor symptoms. Studies have shown that moderate aerobic exercise a few times a week can improve some areas of cognition, as well.

### Depression, Anxiety, & Sleep

Parkinson's symptoms can affect how long you sleep each night, as well as the quality of that sleep. This pattern of interrupted sleep and/or poor-quality sleep can contribute to feelings of tiredness and fatigue through-out the day, but did you know it can also affect your cognition? Improved sleep quality can improve attention and executive function in people with PD.<sup>1</sup> Similarly, depression and anxiety are common non-motor symptoms in people with Parkinson's that can also have an impact

on an individual's cognition. If you are currently experiencing sleep issues, depression, or anxiety it is important that you discuss them with your health care team, as treating these symptoms can be beneficial to cognition as well.

### Cognitive Exercise

On top of exercising and treating other symptoms which affect cognition, there are a few actions you can take to maintain your cognition. Reducing stress, staying mentally stimulated, and being social are a few of the activities which can help by engaging you cognitively. Consider scheduling time to play board games, do a puzzle, read a book, go for coffee with a friend, attend an event, write a story, paint a picture, or do any other task that you enjoy that engages you mentally.



Though you may experience mild cognitive impairment over the course of your Parkinson's journey it is important to continue to do the day-to-day activities you enjoy, exercise, and seek medical advice regarding the symptoms which may have an effect on cognition.

### References

<sup>1</sup> Stavitsky K, Neargarder S, Bogdanova Y, McNamara P, Cronin-Golomb A, "The impact of sleep quality on cognitive functioning in Parkinson's disease," *J Int Neuropsychol Soc.* 2012 Jan;18(1):108-17. doi: 10.1017/S1355617711001482. Epub 2011 Dec 9. PMID: 22152279; PMCID: PMC3758877.

# Parkinson Disease Dementia

Written By: **Declan Beddow**



Dementia is a broad term used to categorize the gradual loss of cognitive functioning, which makes it difficult for people to think, reason and remember. These areas of cognition are impaired to such a degree that it interferes with an individual's ability to complete daily tasks and activities. Around 70% of people with Parkinson's will experience Parkinson Disease Dementia (PDD) at some point in their lives and are most likely to develop it 10 or more years after the initial Parkinson's diagnosis. Parkinson Disease Dementia has a variety of symptoms and may present differently from person to person. This article will briefly discuss how Parkinson Disease Dementia is diagnosed, how it is different from other dementias, and the most common symptoms.

## How is Parkinson Disease dementia diagnosed?

Parkinson Disease Dementia is diagnosed when someone who has been living with Parkinson's motor symptoms (tremor, rigidity, slowness of movement, and/or balance difficulties) for more than one year begins to experience cognitive impairment which significantly impairs their daily life. This includes social, occupational, and personal care difficulties which are not caused by existing motor or non-motor Parkinson's symptoms.

If you are experiencing difficulties with day-to-day tasks, not related to other motor or non-motor symptoms, your neurologist may perform some tests to assess your thinking, memory, and concentration. They may also conduct a medication review, and order blood work to rule out any other causes.

Once a diagnosis of Parkinson Disease Dementia has been made it is important to work with your neurologist or specialist to explore treatment options. There is no "one-size fits all" approach to treating PDD, and the approach that your healthcare team takes will depend on the symptoms you are experiencing and

their severity. Unfortunately, much like Parkinson's, there are no medications which slow the progression of Parkinson Disease Dementia.

## How is it different from Alzheimer's or Dementia with Lewy Bodies?

Alzheimer's and Dementia with Lewy Bodies are other forms of dementia which share some similarities with PDD, but also have distinct differences. Simply put, Alzheimer's tends to affect people's memory and language abilities, whereas PDD tends to affect people's attention, memory, executive function, and visuospatial function. Dementia with Lewy Bodies is similar to Parkinson disease and PDD as it also impacts cognition, movement, sleep, mood, and can cause hallucinations or delusions. In Dementia with Lewy Bodies the major difference is timing of onset. Parkinson Disease Dementia must be diagnosed at least one year after receiving a Parkinson's diagnosis, while Dementia with Lewy Bodies is present at diagnosis or within the first year of diagnosis.

## Symptoms

Symptoms of Parkinson Disease Dementia include cognitive impairment, Parkinson's psychosis (page 10), disorientation, confusion, and mood swings.

Regarding mood swings, a person may become impatient or aggressive, even if they weren't an angry or irritable person previously.

Regarding cognitive impairment, people with Parkinson Disease Dementia experience changes to their cognition which make day to day tasks difficult or impossible to complete. Deficits to cognition usually impact attention, memory, visuospatial function (ability to understand visual information), and executive function (ability to reason and make decisions). For more on cognitive impairment see page 16.





## Thank you!

This year's Step 'n Stride proved to be an incredible weekend of fun, friendship, and fresh air, and was one of our most successful events ever. Almost 1,000 members of our community came out across the province to demonstrate support for people living with or loving someone with Parkinson's.

There was some rain in Lethbridge, Calgary and Cochrane, and a few dark clouds everywhere else, but that didn't dampen anyone's spirits, and when the sun eventually did come out, there was plenty of smiles and friendly faces among all of our participants and volunteers.

We are extremely humbled by the generosity of our participants, volunteers and sponsors, and cannot thank everyone enough.

## Who your support helps

Parkinson's is unique, and everyone deals with it in their own unique way. There is no best way to live well with Parkinson disease or a Parkinson's Plus Syndrome. All Step 'n Stride donations go to support a wide-range of services tailored to the individual and family needs, so we can provide the right support, at the right time throughout the entire Parkinson's journey.

With this approach we can offer strategies, opportunities, and resources to help individuals and families feel more in control, more supported and ultimately, live life the way they want to.







## Thank you Neil McBain & Jeanie McDonell

This year, our Step 'n Stride campaign was very fortunate to be supported with a dollar for dollar donation matching program during the month of August.

This donation was made possible by the generosity of Edmonton's Neil McBain and Jeanie McDonell, who matched \$100,000 in donations to help us exceed our fundraising goals.

There is no way we can fully express our gratitude for this donation, which will go towards the emotional, social, educational and active support provided by Parkinson Association of Alberta.

**\$439,000  
raised across  
Alberta**

Calgary: \$110,000

Edmonton: \$190,000

Red Deer: \$22,500

Lethbridge: \$5,900

Cochrane: \$16,000

Camrose: \$7,300

Grande Prairie: \$7,300

Lloydminster: \$23,000

**Sponsorships: \$57,500**







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