

Parkinson PULSE

Connecting people living with Parkinson disease in Alberta



The

Big

Questions





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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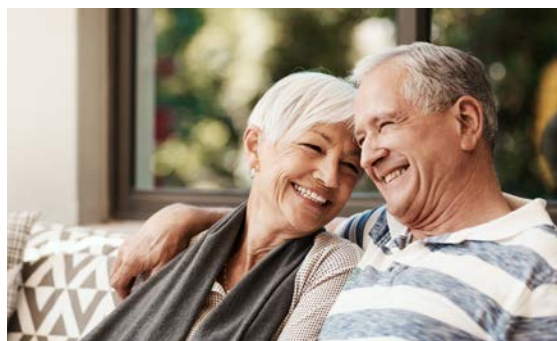
We are here
to Help

**CALL US AT 1-800-561-1911
IF YOU HAVE ANY QUESTIONS
ON OUR PROGRAMS OR SUPPORT GROUPS,
OR JUST WANT TO TALK!**





4 The Big Questions



6 How might Parkinson's Change Intimacy?



9 How does Protein Affect Parkinson's Medications?

Winter 2023

IN THIS ISSUE...

Features

- 4 **COVER STORY**
The Big Questions
- 6 **How might Parkinson's Change Intimacy?**
- 9 **How does Protein Affect Parkinson's Medications?**
- 11 **Can I Ask You a Question about Driving and Parkinson's?**
- 14 **How do I Talk to My Adult Children about Parkinson's?**
- 16 **What Causes Parkinson Disease?**
- 21 **Where do MY Donations Go?**

Every Issue

- 2 **PROGRAM NEWS & UPDATES**
- 3 **MESSAGE FROM OUR EXECUTIVE DIRECTOR**
- 18 **SUPPORT GROUP LISTINGS**

PROGRAM NEWS & UPDATES

Happy New Year Everyone!! Welcome back, we are so happy to share some highlights of the exciting things we've got planned for 2023!

Our Social Gatherings have expanded!

Our Summer and Winter socials were such a hit, that people have been asking us to do more of them! We are happy to announce that we have dedicated the months of April, August and December to Social Events! Check back on our website, social media platforms, and watch our e-newsletters for more details as they get closer!

NEW Support Groups starting in 2023

Over the past year we have received questions from our Parkinson's Community about hosting more specific Support Groups. With that in mind 2023 will see the following new groups join our provincial Support Group line up: Newly Diagnosed, Care Partners – Advanced, Care Partners – Young Onset, and Solo PD. For more information on these groups check out the newly designed Support Groups pages in this issue.

Occupational Therapy

In addition to offering FREE 30-minute assessments both virtually and in person (in the Edmonton Office), our Occupational Therapist Connie Luu has designed a new series of programs that include Handwriting, Fine Motor and Adaptive Aids programs. She is also launching a new Living with PD series! This series will see attendees receive valuable information and practical tips on how to successfully manage those day-to-day life challenges that can come with Parkinson's. Series include Dressing, Bathroom Safety, Travel, Technology, Transportation, and many more! Finally, Connie is taking her expertise on the road with in-person sessions in Vermilion, Lethbridge, and Calgary!

Parkinson Association Educational Series

Building on the success of our monthly PD 101 session, we are adding to our education line up with the following sessions: Parkinson's Plus Syndromes (PD+) 101, Care Partner 101, Introduction to DBS & Duodopa, Housing Options, and two Advanced Care Planning/Government Resources combo presentations – one for those Under 65, and one for those over 65! Last, but certainly not least, we will be adding a Q&A with a Neurologist session, not once, not twice, but FOUR times per year so you can ask the experts your questions!

Research Spotlight

We have decided to switch up our Webinar Wednesdays slightly to alternate with a Research Spotlight to highlight not only current research taking place, but also researchers right here in Alberta! We will do four regular Webinar Wednesdays and four Research Spotlights throughout 2023!

For more information on these or any of the other programs not listed here, please check out our website at www.parkinsonassociation.ca or call us toll-free at 1-800-561-1911.

WHAT'S NEW?



Important Dates to Remember

All PAA Offices will be closed on the following dates:

February 20 (Family Day)

April 7 (Good Friday)

April 10 (Easter Monday)



SOCIAL SINGING PROGRAM



Give your vocal chords a work out every Friday at 10am!

call 1-800-561-1911 for more info

Message from our Executive Director

Happy New Year!

We hope you had a peaceful holiday season.

Winter 2023 Pulse focuses on those questions we get asked that don't really fall into a category big enough to form their own edition. You'll find valuable information for people living with Parkinson's as well as for Care Partners and friends and please, keep the great questions coming. Our Client Service team thrives on helping to figure things out that aren't always so common.

In my role, I get different questions, largely about the financial and fundraising aspects of Parkinson Association of Alberta. It continues to frustrate us that there isn't more government support for Parkinson disease and the important programs that so many find so helpful. While we work hard to advocate with varying levels of government, we find more success through foundations and caring corporate partners who value the impact of our organization. Events, casinos, fundraisers held by others in the community and varying small strategies round out the activities that occupy our time so that we can maintain and hopefully, grow, the support we are able to provide. Despite all these efforts, our single highest source of investment is you, our members.

This past summer, I was reminded that we haven't always been great at expressing our gratitude and that some people feel like all we ever do is ask for money. It caused us to take a hard look and how we fundraise within our community and the need to broaden our reach and relationships in order to build sustainability. Though there are some who think we should be asking more, we have decided to be really intentional about when and how we seek financial support from those closest to us. Moving forward, we will focus our direct to member fundraising efforts on Parkinson Awareness Month (April), Step 'N Stride Walk for Parkinson's (September) and our Annual Giving and Membership Campaign (November/December). Please know how incredibly grateful we are that we are considered in the charitable giving of so many. Your generosity and demonstrations of support motivate us to do more and better every day.



So where does the money go? Like most charities, the largest expenditure is on people. Our staff really are the heart of everything we do. For us, over 60% of our salaries are spent on the direct support of people. 40% account for the people who enable the overall function of the organization so that direct support is possible. These roles include things like Human Resources, Financial Management, Grant Writing, Marketing/Communications and Events and Fund Development. Within the following pages, you will find a breakdown of how funding is invested, including salaries but also considering other costs that comprise our annual budget.

Missing from this graphic is our investment in Research. Alberta based Parkinson's research is so important and we get our direction from our members. Every dollar donated that is designated to research is invested back into Alberta's research community. Our Research Committee works with other experts to source, vet and award financial grants that help to advance research efforts in our province. Those awarded are accountable to Parkinson Association for the use of these funds and to report the outcomes of their funded research. Our process is designed to ensure your investment is responsibly managed and will have the greatest impact.

Thank you so much for taking time to read what is likely my longest Pulse letter in a long time. I hope you find the information here and throughout this edition to be meaningful. Should you find yourself with any lingering questions or thoughts, please don't hesitate to connect with me directly.

All the best,

Lana

Cover Story



The Big Questions

Written By: Brandi La Bonte

**Who? What? When? Where? Why?
Ahhh questions! We've all been asking them
and answering them for the majority of our lives.**

When we were kids, we wanted to know all the things...why is the sky blue? What makes it rain? How do planes fly? When can we go? Are we there yet?

As teenagers the questions were less about gathering new information and more...well let's say self-serving... why can't I...(fill in the blank)? Does he/she like me? Can I have the car? When do we eat?

As we proceed through adulthood, we ask a myriad of questions of others and of ourselves. We ask questions in our own heads, at home, at work, out with friends, at the store, planning a vacation. The list goes on.

At its core, we ask questions to learn more information about something or someone, and we answer questions to provide more information. Questions are knowledge, a learning tool and growth. Questions are powerful because they can spark change. Don't get me wrong facts and information are helpful and necessary, but without the questions we wouldn't have the answers we need. I like questions, asking them is how I learn...well that and reading. This issue of Pulse combines both of these things into one great issue..."The BIG Questions".

As you can likely imagine Parkinson Association of Alberta staff get asked a lot of questions. About Parkinson's. About living well with Parkinson's. About community and government resources. About fundraising and donations. About volunteering. About, well almost anything you can think of. To borrow that old advertising line;"you've got questions, we've got answers." And if we can't, we will do our very best to find you the answer or connect you to someone who does.

In this issue we tackle some of the most common questions we get asked. From questions about Parkinson disease itself, to life with Parkinson's, to where the money raised goes. Of course, this issue doesn't cover everyone's questions, so keep them coming! There are no such thing as silly questions here. The more YOU know, the better informed and more confident you'll be to navigate this journey and make the best choices for yourself (and your loved ones). All our staff are happy to help however we can.

Oh, and one more thing about questions. Questions aren't only about how we learn; they are also an important part of our social skills and help us stay connected to each other. A simple "How are you doing? What's new? Is there anything I can help you with?" can brighten someone's day, let them know you care, and make them feel seen, heard, and included. So don't be surprised if you get a call from us over the next couple of months just checking in to see how you're doing. Happy New Year everyone!





How might Parkinson's Change Intimacy?

Written By: Colleen Davison



During our lives, the concept and practice of intimacy changes and evolves much like our individual maturity. Evolution reflecting our wants and desires transform from the inception of thoughts or ideas, into clumsy beginnings with unfamiliar feelings, expanding into an abyss of longing, desire and need for connection. This journey is fascinating and wonderful; an unknown we pursue as an act or measure of fulfillment and personal identity.

What is intimacy? While we may agree that physical connections are an important part of intimate relationships, enjoying sex and sexual interactions are only a part of the intimacy we require to feel totally connected to our partner. Intimacy is in its very essence emotional and passionate. It is a bond that builds over time. Intimacy is about trust and caring, it is feeling comfortable around the person with whom you share your most vulnerable thoughts, deepest fears, hopes and dreams.

The affect of a healthy sexual experience in a relationship is documented as directly impacting on emotional, physical, and psychological wellbeing.

Emotional intimacy requires a different sub-set of boundaries and understanding. Proposing that an emotionally intimate connection could be as powerful, if not more so, than a physical connection. One could imagine that emotionally stable relationships have the potential to serve as an immunity against potentially destructive influences. It is emotionally tested and true connections that will withstand "off time" changes that Parkinson disease may bring into your life.

Many individuals with Parkinson disease will be fully capable of and interested in maintaining physical and emotional intimacy. Other individuals with Parkinson's may have a completely different experience. Parkinson's may bring with it challenges effecting physical performance, emotional availability, cognitive change, and various other manifestations making intimacy difficult. Additionally, Parkinson disease may cause negative responses towards a loved one, causing a fractured intimacy. This may make it feel as though intimacy is completely inaccessible or void of possibility.

Reflect with me for a moment, remember (as you are able), the love that conveyed you through your relationship, the love that brought you into today.

Before we ever exchange a kiss, or hold hands, we explore opportunities to interact. We create opportunities to share insights, converse, build trust, test trust, extend trust. This is intimacy in its infancy. Laying next to someone, listening to them breath, intimacy. Sharing an all-knowing look across a crowded room, intimacy. These forms of intimacy are responsible for the depth of your love now. Throughout our lives we look to those moments to support us, hold space for us, witness our journey, celebrate us, challenge us, trusting the connection with a deep sense of belonging.

Without transparent conversations, we do not always recognize a pivot away from the status quo, this may unconsciously signal to your partner, there is a division. When changes occur unintentionally, your partner may perceive those changes as a threat. Communication is critical in managing expectations and creating a new path forward when it comes to the changes in your relationship.

How a partner's Parkinson's effects their physical capacity or interest in intimacy becomes necessary

conversation. Transparency demystifies unexpected changes. Responding in tandem, we quiet the fear, we soften the anger, we empower ourselves to find alternative ways to fill the void. Inadvertently creating opportunities for new growth and connection. Living with Parkinson's requires a willingness to **pivot towards change**. Responding together, we are stronger, better prepared to adjust.

Off-time changes, change before a natural readiness or expectation can throw our lives off balance. We may create distance between ownership of the change, in other words, "it's not my fault."

For couples not living with Parkinson's, aging naturally takes care of many conversations and changes in feelings over time. Gradually and mutually accepting transition from active sexual intimacy towards a more intentional expression of love through kindness and caring touch, love notes or acts of kindness. Intimacy changes in the very same way as our relationships evolve, similarly changing and evolving as people.

Let us imagine for a moment, Parkinson's is not part of your life; might you still have challenges around intimacy? Absolutely yes. Intimacy requires commitment and effort for everyone.

Change requires adjustment, a commitment to compromise, and honest conversations about the feelings you navigate. Relaxing around your partner, focusing on experience and pleasure, not performance or endurance, soft touches, memory sharing, story telling, making a date night, fun games or outings, quiet dinners by the fireplace. Intentionally being open to whatever comes that feels right for both of you.

Dealing with changes due to Parkinson disease, presents unique challenges. Often a person will acknowledge feeling hurt or rejected by a partner who does not want or is unable to enjoy sexual or physical connections. This is normal. Decisions to reframe



How might Parkinson's Change Intimacy?

your thinking and feelings around change will be decided by several factors and it can be difficult to know where to start. Begin with inviting a conversation. Set aside dedicated time to discuss your needs. Try asking specific questions, working together to find solutions that work collectively. Understanding that it all revolves around give and take.

- » Do you understand how to create intimacy that feels the way you want/need it to?
- » Do you understand what you are feeling emotionally?
 - Offering pictures of a range of emotions might help a person with cognitive changes (ie: happy, frustrated, curious, embarrassed, etc)
- » Do you know how to ask your loved one for what you need? And do they know how to ask you?
- » Is what you need/want physically possible from your loved one? And vice versa.
- » "What is possible?" is a wonderful place to start!

The Road Not Taken

Two roads diverged in a yellow wood,
And sorry I could not travel both
And be one traveler, long I stood
And looked down one as far as I could
To where it bent in the undergrowth;

Then took the other, as just as fair,
And having perhaps the better claim,
Because it was grassy and wanted wear.
Though as for that the passing there
Had worn them really about the same,

And both that morning equally lay
In leaves no step had trodden black.
Oh, I kept the first for another day!
Yet knowing how way leads on to way,
I doubted if I should ever come back.

I shall be telling this with a sigh
Somewhere ages and ages hence:
Two roads diverged in a wood, and I—
I took the one less traveled by,
And that has made all the difference.

- Robert Frost



If you or your partner have difficulty with this conversation, seeking professional support may be helpful. Conversations around intimacy and Parkinson's can feel overwhelming. A professional can provide you and your partner with strategies and insights navigating intimacy.

Learning to trust, no one single person is responsible, nor can one single person be responsible for all change. Redefining intimacy reassurances both parties that your love is the road that will take you onto your next adventure together. This brings to mind the words of poet, Robert Frost.

Choose the road that brings you back to you, back to your loved one. Trusting your journey will unfold ever gently, lighting in you the courage to step authentically and with grace into your true self, hand in hand with your witness, your love and friend, the one with whom you choose to share your footpath.



How does Protein Affect Parkinson's Medications?

Written By: Emma Torneiro

A diagnosis of Parkinson disease is commonly associated with a prescription for dopamine replacing, enhancing, or mimicking medications to provide temporary relief from the motor symptoms. As we know, Parkinson disease results from the degeneration of dopamine producing cells in the brain. The “gold standard” of Parkinson’s medications is Levodopa, sold under the brand name Sinemet, which effectively replaces the dopamine in the brain to help with daily management of motor symptoms. There are many factors that can influence the effectiveness of the Levodopa medication. However, this article will specifically focus on the relationship between Parkinson’s medications and protein, often called “the Protein Effect”



Let’s imagine you’re going to enjoy a nice steak dinner with your loved ones or close friends. After the meal, your body will

automatically begin digestion of the protein, in this case the steak, which involves the breakdown of the protein into amino acids for absorption in the digestive tract in the small intestine. The receptors within the small intestine responsible for the amino acid absorption are ALSO responsible for absorbing Levodopa for those with Parkinson disease. When oral Levodopa is ingested, it travels to the small intestine for absorption and transportation to the brain through the blood-brain barrier. Since the receptors are only able to absorb limited amounts at one time, **the protein and Levodopa medication compete for absorption.** As a result, the amount of Levodopa that enters your system may be reduced and the medication may feel less effective, may take longer to become effective, or may seem to offer a shortened window of therapeutic relief. The Levodopa medication will remain in the small intestine until the protein has been completely absorbed or the individual has a bowel movement, leading to unpredictable motor symptoms similar to off periods and difficulty with symptom management.

How does Protein Affect Parkinson's Medications?



The common recommendation to resolve the issue of absorption with protein is scheduling Levodopa medications 30-60 minutes before a meal or 1-2 hours after a meal to allow your body sufficient time to digest the protein. The alternative recommendation is consuming larger portions of protein towards the end of the day, as less dopamine may be required in the evening as we prepare our bodies for rest or as symptom management may be less critical.

It is also recommended to drink lots of water! The benefit of drinking more water (*which we should all be doing more of anyway*) includes helping the medication move to the small intestine quickly for absorption and reducing constipation.

If you're struggling to manage the Parkinson's medication on an empty stomach due to nausea, it can often be helpful to take prescribed medication with a smaller snack (ex. saltine crackers or toast) or carbonated beverages (ex. ginger ale). It can be helpful to have smaller snacks throughout the day with small amounts of protein, such as cheese and crackers, to avoid large amounts of protein at meals. This small snacking schedule might also help with nausea from medications. For example, if your medications are scheduled for 11:00 AM, a small snack of cheese and crackers around 10:00 AM might be helpful.

As we learned from Dr. Veronica Bruno during the annual 2022 Hope Conference, the schedule of small snacks can also help with dizziness from orthostatic hypotension and gastric emptying that can improve with medication absorption.

It is important to note that due to the diversity in Parkinson's symptoms and progression, the Protein Effect

may influence each person differently and during different times of the Parkinson's journey. This means that the Protein Effect will **not happen to everyone**, and dietary changes may not be necessary. It is also important to maintain a healthy protein consumption according to the Canada Food Guide to avoid creating additional health concerns from low levels of protein or iron. This means **you should not cut protein out of your diet completely** but work towards modifying how or when the protein is consumed. Seek support from your healthcare team, including neurologist and nutritionist/dietitian, to determine the correct medication schedule and diet for your unique Parkinson's.

Listing of sources of protein:

- » Meat, fish, poultry, eggs
- » Dairy products (cheese, yogurt, and butter)
- » Dairy supplements (Ensure, Boost, whey, protein powders and milk alternative beverages)
- » Plant-based products (beans, lentils, quinoa, soybeans, seeds)
- » Nuts and nut spreads (peanut butter)





Can I Ask You a Question about Driving and Parkinson's?

Written By: Brienne Leclaire

Some of the most frequent questions we get asked from people diagnosed with Parkinson disease are related to driving.

In our culture (and in a province as big and as spread out as Alberta is) driving is very intimately intertwined with independence and control. It's often how we take care of a lot of our day-to-day tasks like getting groceries, or going to doctors' appointments or exercise programs, etc. It's how we maintain a robust social life - visit friends and relatives, go to church, eat out at a restaurant, etc. Driving is one of those milestone markers of freedom we longed for as a teenager; and one that in our later years we often find difficult to give up. Ideally, the conversation around driving should take place long before any challenges arise; that way the choice will still be up to the individual and there will be time to prepare.

In this article we tackle the five questions we get asked most frequently about driving and Parkinson's.

Can I still drive?

In the early stages of Parkinson's, driving can usually continue as before. Medications will help control symptoms but be aware of side effects that may cause sleepiness. Parkinson's can affect driving in a multitude of ways, with risks increasing as the disease progresses. These can include, but are not limited to:

- » A person's ability to multitask – driving is all about multitasking!
- » Cognitive issues. Thinking, concentration, judgement, and insight can be affected by Parkinson's so it can take longer for decisions to be made. They can also lead to disorientation and confusion (from missed turns to getting lost)
- » Slowness and stiffness make it difficult to move your head, making it hard to shoulder check
- » Tremor or extra movements (dyskinesia) in arms and legs may affect steering, breaking, and accelerating
- » Reaction times are slowed making it harder to quickly react to something suddenly moving into the path of the car – a child, another car, an animal
- » Vision issues. Blurred vision, changes in depth perception and difficulty with eye movements can be a problem, making it hard to see and follow what is around you
- » Medications for Parkinson's may make you sleepy or confused

Do I have to report my Parkinson's diagnosis to continue driving?

In Alberta, you are required by law to report any medical or physical conditions or changes in health that may affect your ability to safely operate a motor vehicle. But what does this mean?

First and foremost, having a medical condition does not necessarily mean your driving will be restricted. The type of illness, treatment, medications, and other factors are reviewed to determine effects on your fitness and ability to drive. Parkinson disease is considered a medical condition that can affect driving; and so, this means that when you receive a Parkinson's diagnosis you are to contact Driver Fitness and Monitoring to report your medical condition. Once you have reported you will need to get a medical exam from your doctor. The doctor will evaluate whether your condition affects your ability to drive safely. Your doctor may also recommend a road test or further cognitive or medical testing before completing your driver's medical. Most general practitioners and specialists as well as nurse practitioners can complete medical forms required to renew your driver's licence. A basic medical evaluation looks at the key areas that may affect the ability to safely operate a motor vehicle like vision, hearing, cognitive abilities, motor abilities, and overall health. It is important your doctor lists your medical conditions names and stability on the form to make the process easier and give Driver Fitness a better understanding of your condition's stability.

After the medical exam documents are submitted you will receive a letter back from Driver Fitness and Monitoring outlining their decision, any conditions on your license and how often you need to renew the



medical exam. If they need more information to make a decision, they will ask you to send the required documentation as requested in the letter by mail, email or fax to Driver Fitness and Monitoring.

How often you need to receive the medical examination depends on a few factors. Your condition, symptoms, and the progression of your condition. If your doctor signs off on the medical examination form that your condition is stable and there are no concerns for it impacting driving it can be up to five (5) years before you are required to get another one. Depending on condition, symptoms, and the progression of your condition the term length can be anywhere between every five (5) years to every year.

It is important to note that a medical examination required to obtain or renew a driver's licence is not insured under the Alberta Health Care Insurance Plan. As an uninsured service, physicians can charge patients for drivers' medical exams.

Driver Fitness also looks at age as a part of their drivers monitoring. This is separate from the medical condition monitoring and applies to everyone regardless of medical conditions. For Class 3, 5, 6 and 7 driver's licences, medical examinations are required at age of 75, age of 80, and then every two (2) years after age of 80.

If you do not report your medical condition and there is an accident depending on the accident cause, and other factors your insurance might not cover the accident and you can possibly be charged. If you fail to submit documentation requested by Driver Fitness and Monitoring your license can be revoked/suspended.



Does my Parkinson's diagnosis impact my insurance?

A Parkinson diagnosis does not impact your vehicle insurance rates. Insurance companies use a formula based on several identified risks to determine the price of your auto insurance policy. These risks include where you live, your age, vehicle type, how much you drive, driving record and any past insurance claims. A reminder as indicated above, failure to disclose your medical condition to Driver Fitness and Monitoring could invalidate your insurance policy.

Can someone report my driving? Can my doctor? If they do report me what happens?

In short yes someone can report you to Alberta Transportation if they believe you are unsafe or unfit to drive. While doctors and other medical professionals are not legally required to report suspected medically-at-risk drivers. They are protected from legal action if they choose to report a driver. Your doctor cannot take away your driver's licence; only Alberta Transportation, as the Registrar of Motor Vehicle Services, has the authority to cancel or suspend a driver's licence.

When a report is made it is investigated and you will be contacted (typically by letter) to provide information or to undergo drivers' fitness examination relating to the concerns for drivers' fitness to drive. The Registrar has the authority to require that a driver participate in a medical examination, place special conditions or restrictions on a driver's licence, and suspend a driver's licence. These actions will only be taken where there are reasonable and probable grounds to believe that the driver is a safety risk to themselves or others.



If you do not agree with a decision made on your file, you can contact Driver Fitness and Monitoring who will review your file and consider your medical report and other information such as medical documentation, your driving record and your road test results to determine your ability to drive safely.

When should I stop driving?

This can be a challenging question to answer. It may take many months or years after diagnosis for Parkinson's to interfere with activities of daily living, such as driving. If you are unsure of how to determine if you (or your loved one) are still safe to drive, ask yourself the following questions:

- » Do I feel safe while driving? Do my loved ones/others feel safe driving with me?
- » Have I been involved in any "close calls", accidents or traffic infractions that were my fault and could be attributed to any of the risks listed above?
- » Do I struggle to operate the vehicle? Have I gotten temporarily lost or turned around while driving a regular route?
- » Have loved ones expressed concerns about my driving ability?

If you answered yes to any of the above questions, it is time to have the conversation. With such a strong connection to independence, the decision to stop driving can be a difficult decision to make on your own. Including your loved ones and medical team can also help you evaluate if you are still safe to drive.

While recognizing that driving is an important part of maintaining independence; it is also equally important to remember that driving is a great privilege and responsibility. Engaging in open and honest conversations about driving will ensure you, your loved ones and everyone out on the roads stays safe.

References

Driver Fitness Monitoring; Medical Conditions and Driving. 2022 Government of Alberta. <https://www.alberta.ca/medical-conditions-and-driving.aspx>

Understanding Your Insurance Rates. 2004-22 Automobile Insurance Rate Board. <https://albertaaairb.ca/for-drivers/shop-the-insurance-market/understanding-your-insurance-rates/>



How do I Talk to My Adult Children about Parkinson's?

Written By: Alana Wright

Let's face it, having tough conversations with your kids is never easy. Even when children become adults, you still hope to spare your child from stress and worry.

Receiving news that a parent has a chronic disease is likely to come as an emotional shock, even to adult children. There are a lot of ways an adult child might react to hearing this news. They may want to drop everything and rush to your side, feel helpless or guilty for not being able to do more, or they might shut down and need some time to process their emotions. There is no way for you to predict how your child might react, but you can do your best to be prepared for a conversation.

First, it's important to consider waiting until you feel comfortable and have all the information you need. By learning about your diagnosis, treatment plan, and prognosis before talking to your child, you can be more

prepared to answer any questions they may have. This allows you to give a complete picture of the situation, which may help in decreasing any worry they may have.

Second, it is important to be open and honest with your child. It can be difficult to share your emotions, especially if you are worried about burdening your child with your



feelings. However, if you're sad, worried, or angry, tell them – it encourages your child to be open about their feelings too. This will keep the conversation going and allow your child/children to feel included and involved. Encourage them to ask any questions they may have or learn about the disease with you. For example, if your children want to learn more about the disease, encourage them to do research or attend information sessions with you. Parkinson Association of Alberta offers a monthly PD 101 education session and 1:1/family sessions that are open to everyone. Both are a great place to ask questions and gain information about Parkinson's!

Third, let your child help! Most adult children want to be involved and would like to help one way or another! However, unless you raised mind readers, they may need you to tell them HOW they can help. Consider asking them to sit in on a doctor's appointment and take notes for you or drive you to an appointment, support group or exercise program. You can show your children how to navigate a diagnosis and teach them



skills such as asking for help, interacting with specialists, or advocating for yourself. Not only are you having a conversation with your child, but you are also encouraging them to be involved.

Fourth, it's ok to say no and have boundaries. For some adult children hearing that their parent has an illness puts them into "go mode". They want to "fix" everything. And while the sentiment is heart-warming, it can feel overwhelming to the person on the receiving end. In this case a balance is best. Keeping children informed and encouraging them to get educated about Parkinson's, AND maintaining healthy boundaries are important.

At the end of the day, it can be hard to have these conversations with adult children. You were the one to raise them and were the person supporting them during difficult times. Now, it can sometimes feel like the roles are reversed, and that can be uncomfortable. It can be hard to see your adult child as someone you may be able to lean on for help, but they are there for you. Remember that your adult child can still have their own life while helping you. You can accept their help and still encourage them in their work, hobbies, and relationships. All you need to do to start is have a conversation!





What Causes Parkinson Disease?

Written By: Declan Beddow

This question is really a combination of two questions which are connected but must be answered separately. First, what causes the symptoms of Parkinson disease? And second, what causes someone to develop Parkinson's?

To address the former question, we must look at what is happening in the brain of someone with Parkinson's.

The symptoms of Parkinson disease are primarily caused by a lack of dopamine in the brain. Dopamine is a neurotransmitter which allows the brain to send signals between itself and other parts of the body, via nerve cells. When there is a lack of dopamine in the brain these nerves fire abnormally, resulting in symptoms of Parkinson's.

Now, you may be asking yourself, "but why is there a lack of dopamine in the brain?" For that answer

we must look to the part of the brain responsible for dopamine production, the **substantia nigra**. Nerve cells within the substantia nigra are responsible for the production of dopamine and the relay of messages which plan and control the body's movements (everything from walking and speaking to your digestive system). By the time a person is diagnosed with Parkinson's they have lost between 60 - 80% of these dopamine producing nerve cells.¹ As the disease progresses these cells will continue to die.

Unfortunately, this is where things become a bit foggier. The cause of the cell death within the substantia nigra is currently unknown. The good news is that research is currently being done to answer this very question. Some researchers believe it may be related to the accumulation of a protein called Alpha-synuclein within the nerves of the substantia nigra. Others are exploring the possibility that it could be related to a dysfunction in the bodies mitochondrial (the mitochondria are the powerhouse of the cell) or waste removal systems.²



Now that we have explored what is happening in the brain of a person with Parkinson's to cause symptoms, we need to talk about the other half of the question "What causes someone to develop Parkinson disease in the first place?" The short answer is that the development of Parkinson's is caused by some combination of genetics and environment³, though this answer is somewhat unsatisfactory as most everything in life can fall into one of those two categories. So, what do researchers mean when they are talking about genetics and environment?

Researchers have identified many genes which may play a role in the development of the disease and attribute approximately 10% of Parkinson's cases to genetics. So, this means that most people with Parkinson's have no genetic link⁴. Also, just because you have a Parkinson's-related gene doesn't mean you are guaranteed to develop Parkinson's either, actually far from it, most people with a Parkinson-related gene **won't** develop Parkinson's. In a small number of cases Parkinson disease is considered inherited and can affect multiple family members, but even in those cases there is no guarantee that the children of someone with inherited Parkinson disease will develop Parkinson's (though they might be at an increased risk). That is why we must look to environmental factors as well.

References:

¹<https://www.ninds.nih.gov/health-information/patient-caregiver-education/hope-through-research/parkinsons-disease/parkinsons-disease-challenges-progress-and-promise#:~:text=By%20the%20time%20Parkinson's%20is,brain%20systems%20are%20also%20damaged.>

²<https://cureparkinsons.org.uk/what-is-parkinsons/the-science-behind-parkinsons/>

When discussing environmental factors, it is important to note that from a scientific perspective it is not only about where you live, the air you breathe, what you consume, your career, et cetera, it is everything that you do, have happen to you, and/or are exposed to throughout your life. Certain environmental factors have been linked to an increased likelihood of developing Parkinson's; these include (but are not limited to):

- » Head injuries and traumatic brain injuries.
- » Exposure to certain metals/heavy metals.
- » Geographical location. Some parts of the world have a much higher prevalence of PD than others. In the US for example, there are significantly more people with PD in the Midwest and Northeastern parts of the country⁵.
- » Exposure to pesticides and herbicides.
- » Exposure to solvents and Polychlorinated Biphenyls (PCBs). These are man-made chemicals which may be used in a variety of industries⁶.

The environmental factors listed above have been identified as risk factors which may increase a person's likelihood to develop Parkinson disease, though these risk factors alone do not cause Parkinson's. This is why researchers believe that some people may have a genetic make-up which makes them more susceptible to the effects of these environmental factors. It is likely this combination of genetic susceptibility and exposure to risk factors in the environment which causes an individual to develop Parkinson disease.

I hope this article has helped to explain the current understanding of Parkinson disease and what causes it. We don't have all the answers yet but, through research, we are ever approaching a better understanding of this disease and its causes.

³<https://www.parkinson.org/understanding-parkinsons/causes>

⁴<https://www.parkinson.org/understanding-parkinsons/causes/genetics>

⁵<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2865395/>

⁶<https://www.parkinson.org/understanding-parkinsons/causes/environmental-factors>

2023 Support Groups

We are happy to present our 2023 Support Group line up. With FOUR new additions to our Provincial Groups our support group offerings now total 41. Another item to note is the absence of April, August, and December in the line up; we are excited to announce this is because we will be hosting fun and engaging SOCIALS in those months instead!!

A note about registering each month for Support Groups. Groups require a minimum number of attendees to run successfully, if we do not have enough registrants the Support Group will unfortunately be cancelled. **It is important to register at least one (1) day BEFORE your support group is slated to take place to help ensure that the Group does not get cancelled due to low registration.** Registration will also ensure that YOU receive the most up-to-date information about your Group (including changes in venue, cancellation due to sickness, extreme weather, or low registration).

To register each month please call toll-free **1-800-561-1911** or talk to a Client Services Coordinator.

PROVINCIAL (ZOOM/CALL-IN ONLY)			
1st Tuesday	of every month no group in January	DBS/Duodopa (for those who have had one of the surgical interventions for PD and their loved ones)	1:00PM
1st Tuesday	of every month (except October) Starts February 2023!	Care Partners – Advanced (NEW GROUP) (for those whose loved ones with PD or PD+ are in or transitioning into Long Term Care)	10:00AM
1st Thursday	of every month Starts February 2023!	Newly Diagnosed (NEW GROUP) (for those who are newly diagnosed or have had PD for less than 2 years and their loved ones)	1:30PM
2nd Wednesday	of every month	Young Onset (for those diagnosed Young Onset who are under 60 and their loved ones)	7:00PM
2nd Thursday	of every month Starts April 2023!	Solo PD (NEW GROUP) (for those diagnosed with PD who do not have a spouse or Care Partner)	1:30PM
3rd Thursday	of every month	General Parkinson's (for those whose have been diagnosed with PD and their loved ones)	10:00AM
3rd Thursday	of every month	Care Partners (for those whose loved one has PD or PD+)	1:30PM
3rd Saturday	of every month	Parkinson's Plus (PSP, MSA, CBD, & DLB) (for those diagnosed with a Parkinson's Plus Syndrome and their loved ones)	12:00PM
4th Tuesday	of every month	Widows (Closed Group) (for those who have taken or are currently attending our Widow's Program)	10:00AM
4th Wednesday	of every month (except December)	Care Partners – Young Onset (NEW GROUP) (for those whose loved one was diagnosed Young Onset and is currently under 60)	7:00PM

2023 Support Groups

Please note for Support Group months listed below –
BLACK text indicates an in-person group, while GREEN text indicates a Zoom/Call-In group

CALGARY REGION			
3 rd Tuesday	Jan, Feb, Mar, May, Jun, Sep, Oct & Nov	Airdrie	10:00AM
1 st Tuesday	Feb, Mar, May, Jun, Oct & Nov	Calgary Northwest	10:00AM
1 st Thursday	Feb, Mar, May, Jun, Oct & Nov	Calgary Northeast	10:00AM
3 rd Tuesday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Calgary Care Partners <i>(online only)</i>	1:30PM
3 rd Thursday	Jan, Feb, Mar, May, Jun, Sep, Oct & Nov	Calgary Southwest	10:00AM
4 th Tuesday	Jan, Feb, Mar, May, Jun, Sep, Oct & Nov	Calgary Southeast	10:00AM
4 th Tuesday	Jan, Feb, Mar, May, Jun, Sep, Oct & Nov	Calgary Central	2:00PM
2 nd Thursday	Jan, Feb, Mar, May, Jun, Sep, Oct & Nov	Canmore	1:30PM
2 nd Thursday	Jan, Feb, Mar, May, Jun, Sep, Oct & Nov	Cochrane	10:00AM
4 th Thursday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	High River/Nanton/Okotoks	10:00AM
1 st Thursday	Feb, Mar, May, Jun, Oct & Nov	Strathmore	1:30PM
EDMONTON REGION			
2 nd Wednesday	Feb, Jun & Oct	Camrose	1:00PM
1 st Wednesday	Feb, Mar, May, Jun, Jul, Oct & Nov	Edmonton South	1:00PM
1 st Thursday	Feb, Mar, May, Jun, Jul, Oct & Nov	Edmonton Care Partners	10:00AM
TBD	TBD	Edmonton West <i>(new group coming soon)</i>	TBD
3 rd Wednesday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Edmonton Central <i>(NEW TIME)</i>	2:00PM
4 th Tuesday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Fort Saskatchewan	1:00PM
4 th Tuesday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Leduc	6:30PM
4 th Thursday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Parkland <i>(Spruce Grove/Stony Plain)</i>	10:00AM
3 rd Tuesday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	St Albert	10:00AM
2 nd Tuesday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Sherwood Park	1:00PM
GRANDE PRAIRIE REGION			
2 nd Wednesday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Grande Prairie	1:00PM
LETHBRIDGE & MEDICINE HAT REGION			
3 rd Thursday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Lethbridge	2:00PM
3 rd Wednesday	Jan, Mar, May, Jul, Sep & Nov	Medicine Hat	12:00PM
LLOYDMINSTER REGION			
3 rd Tuesday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Bonnyville	10:30AM
4 th Thursday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Lloydminster	2:00PM
1 st Tuesday	Jan, Mar, May, Jun, Jul, Oct & Nov	Vermilion	10:30AM
RED DEER REGION			
4 th Wednesday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Lacombe <i>(NEW TIME)</i>	1:00PM
2 nd Wednesday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Olds	1:30PM
3 rd Wednesday	Jan, Feb, Mar, May, Jun, Jul, Sep, Oct & Nov	Red Deer <i>(NEW TIME)</i>	1:00PM
2 nd Thursday	Feb, Jun & Oct	Rocky Mountain House	2:00PM

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

First Name: _____ Last Name: _____

Address: _____

City: _____ Prov: _____ Postal Code: _____

Phone: _____ Email: _____

Select One: ☐ I am a Person Living with PD/PD+☐ Family Member/Friend☐ My Spouse/Partner has PD/PD+☐ Stakeholder/OtherI would like to receive **email** news updates from PAA**YES****NO**I would like my Pulse Magazine **mailed** to me**YES****NO**

I would like to learn more about volunteering

YES**NO****I want a staff member to contact me about PD and/or PD+, Programs and/or Services****YES****NO**

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

☐ **ADDITIONAL \$15 Secondary Membership**

Name: _____ Email: _____

Address: _____

Select One: ☐ Spouse/Partner☐ Family Member/Friend☐ Stakeholder/Other

I would like to receive updates from PAA: email news, Pulse Magazine by email

YES**NO****PAYMENT**

Call 1-800-561-1911 to pay by Credit Card or E-transfer

Or Attach Cheque in the Amount of:

Total \$ _____

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

WHERE ^{do}_{your} DONATIONS GO?

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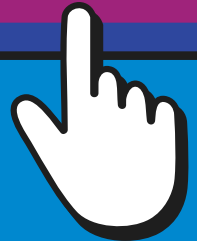
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