

Parkinson PULSE

Connecting people living with Parkinson disease in Alberta



Moving Forward

*Supporting our
Community
through Diversity*





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Winter 2022

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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; 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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Happy New Year! We hope you have enjoyed a peaceful holiday season.

Last year was a tough one for so many in our community. For those of you who are experiencing particularly difficult aspects of living with or loving someone with Parkinson's or Parkinson's Plus, we extend a special word of support. Please know we are thinking of you.

Hardships often bring unexpected but heartwarming bright sides, and we have experienced this as well. It's such a privilege for us to be able to share in the highs and lows of the Parkinson's journey.

Late last year, I had the privilege of meeting with former board member, Ken Papp, and his wife, Michelle Sampert, at our Calgary office. Michelle works for Scotia Wealth Management, who have an employee contributed charitable fund called "Sharing the Wealth". Michelle nominated Parkinson Association of Alberta to receive a grant this year and graciously agreed that I could share some of her submission.

"My husband, Ken, was diagnosed with Parkinson Disease in 2014, and like many life altering situations, when one partner has PD, you both have PD. Our involvement with the Parkinson Association of Alberta started after we attended our first young onset support group shortly after Ken's diagnosis. I would get support as a care-partner and Ken would get support as a patient. As a completely self-funded entity, we felt we needed to support the PAA in any way we could. It started small, from bringing creamer or treats for the weekly meetings, to driving other PD patients to meetings, events or appointments."

The single biggest source of income for PAA is their annual Step n' Stride. As a couple, we raised the most donations in Alberta for this event in 2015, 2016, and 2017, and inspired others to meet or beat us, which did happen! Ken was on the PAA board of directors from 2016-2020 as a patient advocate. Over the last couple of years and during COVID, our direct involvement has lessened, mostly because of Ken's physical deterioration, but the PAA still helps us, other clients and their families every day and still deserve our help.

We didn't know we were entering a long, dark tunnel when we noticed a small quiver in Ken's left index finger. It takes a very long time to get from your doctor to a neurologist to the specialist neurologists at the movement disorder clinic. And when they finally tell you, "we think you have Parkinson disease", it's like getting hit by a train. then ask, "what happens now", and they really can't answer. You are facing another tunnel, this time, there is light at the end of it which for us was the Parkinson Association of Alberta. Their knowledge, support, and community are the true inspiration for how to live with an incurable, progressive disease.

Being involved with the PAA and their works gives me the hope and strength to be optimistic, productive, and grateful for this life."

Thank you, Michelle & Ken, and thank you to the employees of Scotia Wealth Management for your generous donation of over \$15,000.

This edition of Pulse is all about the work of this Organization and the opportunities for people to become part of our community when and in the way that is right for you. We continue to learn and respond where we can and appreciate the feedback and input we receive. We are evolving a combination of tried and true programming with some new ideas this year and look forward to seeing you in person once again.

Lana Tordoff,
Executive Director

We Want to Hear from You

The challenges and success you share helps 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 both our Summer 2021 "Non-Motor Symptoms of Parkinson Disease – Greatest Hits Volume 1" AND our Fall 2021 "Cognitive & Psychological Changes in Parkinson's" issues. Thank you for sharing your thoughts and feedback!



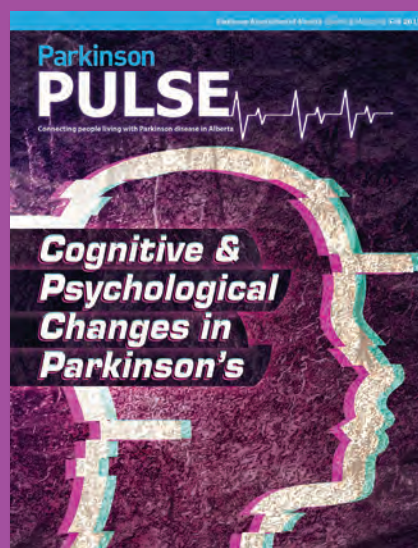
Thank you for the articles on 'Non-motor Symptoms' in the summer edition of Pulse. I started experiencing Nocturia in about May/June of 2021 and then in August started having problems with blood pressure. It was not until I discovered the articles that I was able to clearly describe to the doctor what was happening to me. We are now concentrating on managing the Orthostatic Hypotension and using urinals means my sleep is much less disrupted.

I was first diagnosed with Parkinson's in 2013 at age 79. I have had only slight tremors in my hands though they are now increasing. My main problems have been handwriting, much slower walking and constipation. My wife passed away in May 2015 and, by late 2018, my family had convinced me to move to an assisted living facility. Until March 2020 I was dancing 2 times a week and exercising regularly at the Y. In July 2020 I fell and broke my left hip. After about 10 days in hospital, I spent a month in rehab at the Glenrose. Then in February 2021 I fell again, and this time broke my right femur which resulted in another month in the Glenrose after surgery. I am now unable to move about without a walker and that means it takes much longer to get things done.

I just received the Fall 2021 edition of the Pulse and look forward to reading the articles. Again, thank you for your interesting and very informative articles.

- Don Junk

First, I want to thank you for all the work you do supporting the Parkinson's community and keeping us in touch with the Pulse magazine. Thank you for devoting the Fall edition of the magazine to the mental challenges that up to 40% of patients can develop in the advanced stages. For too long mental issues have been something nobody wants to talk about. Not to minimise in any way the physical hardships brought on by Parkinson's but too many folks think this disease only affects movement. Colette has been at Dickinsfield LTC for seven months now and I am grateful to have access to this kind of help. This cannot be managed alone at home.



Over the years some have looked at me in disbelief when I would try to describe what Parkinson's was doing to my wife Colette. The articles in the magazine really mirror's Colette's symptoms. Now when people ask how my Girl is, I just hand them the magazine to look through. That is easier on me.

Keep up the good work.

- Ed & Colette Langevin

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.



Moving Forward

Supporting our Community through Diversity

Written By: **Brandi La Bonte**

Hello friends, it's been a weird couple of years hasn't it? A lot has changed within Parkinson Association of Alberta since the pandemic began almost two years ago. New leadership, new programs, new delivery and a renewed sense of purpose and commitment to the people we serve - those living with and affected by Parkinson disease and Parkinson's Plus Syndromes. With that in mind (and it being the beginning of a brand, new year), I thought this magazine would be a great opportunity to reconnect and acquaint ourselves to you!

Parkinson Association of Alberta has a physical presence in Calgary, Edmonton, Lethbridge, Lloydminster, and Red Deer. Grande Prairie and Medicine Hat are also physically covered by Client Services staff. Our primary service area is province-wide, though we do have clients from other provinces and territories as well as the US. We are a small but mighty group of sixteen across Alberta. Lana, our Executive Director, and our Administrative, Fund Development and Communications staff make up half of the team, with the remaining eight (including myself) making up the Client Services Team.

We know Parkinson's is unique, and everyone (both the individual diagnosed and their loved ones) deals with it in their own unique way. There is no, "one" or "right" way to live well with Parkinson disease or a Parkinson's Plus Syndrome. With that in mind, we are pleased to offer a wide-range of supports and services tailored to the individual/family needs to 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.

The pandemic showed us that help and support are so vital, especially when we cannot be out and about in public. We are pleased to let you know that our services are offered and can be accessed via a variety of platforms – in person, online, and via telephone (including a tollfree line); ensuring the no matter where people with Parkinson's live, we are here to help! We offer a variety of programs that fall into one of four categories: Support, Education, Active, and Outreach. Each with its own unique purpose and way of helping people living with and affected by Parkinson's.

Our Support Programs are designed to provide both emotional/mental health and practical support options to individuals, care partners and families throughout their journeys with Parkinson's. The following programs are currently offered and/or being developed: One-on-One/Family Support, Support Groups, new Care Partner Programs, and a new Ambiguous Loss & Grief Program.

Our Education Programs equip people with the high-quality knowledge and tools they need to feel empowered to take control of their lives, advocate for themselves and make decisions that will help themselves and/or their loved ones live well with Parkinson's. These programs currently include: Information & Resources (including disease-specific and community and government resources), Webinar Wednesdays, a new Parkinson's 101 Program, and so much more.

Our Active Programming is all about taking action, staying motivated, and staying connected...to keep bodies, minds, voices and hearts strong and healthy. These programs are divided into four categories: physical, voice/speech, cognitive and social. With programs happening both in person and via online platforms, there is a variety of options to get people active. Programs include, but are not limited to: exercise, boxing, Thinking, Memory & Concentration, singing, our PACE speech program in partnership with the University of Alberta, and our new Occupational Therapy programs also in partnership with the U of A.

And finally, our Outreach Programs. At Parkinson Association of Alberta we are big proponents of "when you know better, you do better;" which is why we make it a priority to not only educate those in the community about Parkinson's (through presentations and in-services); but keep learning ourselves.

Of course this is just a small highlight, throughout this issue the Client Services Team (and some of our clients) will tell you more about the supports, services and programs we offer. As I wrap up I just want to say... Happy New Year!! We cannot wait to reconnect with you in what I'm sure will be an exciting new year!

Support as Unique as You Are!

One-on-One/Family Support

By: **Declan Beddow**



One-on-One/Family Support is a bit of a nebulous service we offer here at Parkinson Association of Alberta. By that I mean it could be a one-time sit-down to discuss Parkinson's after first being diagnosed, working with your CSC to find specific government and community resources, or just talking through life's difficulties with someone who understands Parkinson's. In this article we will be discussing the latter.

A few weeks ago, I sat down with Carolyn, a client of mine who has been attending bi-weekly support sessions since February, to discuss her experience with one-on-one support. Carolyn was officially diagnosed with Parkinson's in 2011 but can remember experiencing the initial symptoms in the late 90's. *Some quotes have been modified for brevity.

Can you share what sort of things we talk about when we meet?

We talk about anything and everything. From medication to other forms of managing Parkinson's, like DBS and Duodopa. We've talked about feeling inadequate. We've talked about relationships. We've talked about sexuality. Symptoms of Parkinson's that I may not have really thought belonged there, but turns out they do, like losing memory, losing concentration, and just helping me work my way through a lot of stuff.

And I've even had days where I say no that's okay, you can go do something else because I'm doing well."

In what way has it been helpful to talk through these things?

You know, I don't know how other people perceive it, but I find Parkinson's a really lonely disease. Everything that you face is really hard to explain to someone - what it feels like or how it affects me. I find it hard to talk to my husband about it, he tries - he tries his hardest, but how could he possibly understand if he hasn't experienced it? And to talk to someone like you, who does have some idea, from

talking to other clients, and having some idea of exactly what's going on is huge.

It makes such a difference. It's like shining a light on something that usually stays really, really dark, and helping me see into some of those dark corners that do nothing but provide nightmares. I'm really battling here, but it is a nightmare, and to try and do that without anybody else understanding - I don't know if I could do it. I don't know how I did it for so long. It gives me a sense of perspective. You have often given me a sense of hope when I was feeling quite hopeless, and a sense that it is okay to keep trying and doing the very best that I can, rather than just giving up.

Is there something specific that you can recall that has stuck out from our talks?

Most of the help you have given me is along the lines of hope. I know it's not a terminal illness but it's not something that is ever going to get better. And I really struggled to accept that but talking with you reminds me that I don't have to jump to the end, when it's over, that there's still life to live and things I can do. Even if it's not the same that it used to be.

Any advice for someone who is considering setting up an appointment with a CSC but might be on the fence about it?

I would say don't hesitate, trust yourself and trust the Coordinator to keep the conversation where it works for you. Nobody is going to force you into saying things you don't want to say. But it gives you the opportunity to get more information, to get some compassion, to get the general sense that it's okay to belong to this community. So, I would say don't hesitate and allow yourself to trust.

Anything else you would like to add?

I'm gob smacked that the service is free, and it's truly a blessing that we don't have to pay for this.

As you can imagine, One-on-One Support is a difficult service to define because it really depends on what YOU want or need. I do hope however, that Carolyn has given you a better sense of what we are able to offer to our clients. We are here to support you in whatever ways we can. If you think you would benefit from one-on-one/family support please call your Client Services Coordinator. Thank you to Carolyn for agreeing to be interviewed for this article.

Caring for the Carers

Care Partner Programs

By: *Brienne Leclaire*



The person with Parkinson's or Parkinson's Plus is not the only one thrust into the Parkinson's journey. Care Partners walk along side their loved ones throughout the Parkinson's journey. Care Partners face their own unique journey supporting someone with Parkinson's. Parkinson Association of Alberta is here to support both people with Parkinson's and their loved ones. This article outlines some of the Care Partner specific support we offer.

We are pleased to offer four (4) **support groups** specifically for Care Partners. Support groups provide a space to share with, meet and connect with other Care Partners. Creating this space gives the opportunity to share your own knowledge as well as learn from the facilitator and other Care Partners. When attending a group, you can expect to talk, share, and learn in a safe and caring environment. We offer both online and in person care partner support groups. There are several regional groups that meet in person and two provincial zoom support groups that meet online.

Another wonderful resource is our one-on-one and family support. Our amazing Client Services Coordinators are happy to meet with you individually as a couple or family. This support can help discuss on going issues, needs or feelings. As well as connect you and your loved one to community and government resources.

During the pandemic we developed a variety of more structured programs specifically for Care Partners. These programs target different stages of the care partner journey.

Our **Care Partner Support Program** (coming this March) is a seven-session program that aims to help Care Partners navigate their Parkinson's journey, prevent burnout, connect with support and resources, provide connections with other Care Partners, and provide a safe and supportive space to share and discuss their struggles, emotions, and journey in a confidential environment.

Our newly created **Transitions to Care Program** (coming this March) focuses on managing and navigating that time when you are no longer the primary care partner for your person. They have transitioned into care or are being cared for by others. This program will help you navigate this new stage, advocate for your loved one in care, as well as focus on rediscovering yourself, re-establishing relationships and taking care of your self and loved one during this time.

Our recently launched **Widows and Widower's Program & Support Group** is a two-part program designed to help Care Partners cope with the loss of their spouse who had Parkinson disease. Part one is an 8 - 10 session program which will provide the participants: education on grief and loss, coping strategies, relatable stories, and relevant discussion topics. Part two is an ongoing support group in a similar style to a Care Partners support group.

While not just for Care Partners, we are also excited to launch our long awaited **Ambiguous Loss and Grief Program** this March. This program, for both Care Partners and people with Parkinson's, is aimed at exploring and understanding the emotional and psychological mechanisms of ambiguous loss/ anticipatory grief, the function of grief, intersections of grief and loss in Parkinson's (think the life you planned vs life after Parkinson's), management strategies, and healthy grief.

Care Partners are an important part of what we do and an important support in the Parkinson's journey. Recognizing the role Care Partners play in their loved ones' lives and the journey they are on as well we work to support Care Partners throughout their journey. Our website offers additional information and resources for Care Partners as well. Check us out at parkinsonassociation.ca to register for any of the above listed supports or contact your local Client Services Coordinator or call us toll free at **1-800-561-1911**.

Active Programming

By: Jordan Wiebe



It is no secret that being active is one of the best things you can do for yourself, especially if you have Parkinson disease. There is no shortage of information about things you can do to manage your Parkinson's, but we know it can sometimes be overwhelming to determine what is best for you. This can be especially challenging if you are trying to manage your Parkinson's while integrating new activities into your everyday routine. While it may be daunting at first, Parkinson Association of Alberta is here to help you figure out the best living well options for you throughout your journey with Parkinson's. We offer several different types of active programs that are designed with you and your needs at the forefront – physical, voice/speech, cognitive, and social.



Physical Programming includes (but is not limited to): exercise and boxing programs, occupational therapy programs (coming soon); as well as Motivation Mondays which is your weekly access to a free, easy workout!

Voice/Speech Programming includes (but is not limited to): PD & Singing, Social Singing, and PACE (our combination group and 1:1 sessions offered in partnership with Speech Language Pathology staff and students from University of Alberta Faculty of Rehabilitation Medicine).

Cognitive Program includes our on-line Thinking, Memory & Concentration Program.

Social Programs include (but are not limited to): Summer socials, holiday celebrations, social groups & coffee chats, painting, bowling, etc.

Now I could drone on about why you should be active, how it can benefit you, or the technical details of our programs; but I won't. Why not? Well, while those things do matter, they are not the most important things to consider when choosing to participate in our active programming. Instead, I invite you to consider the community you are joining and the connections you

can make within that community. Being a part of an engaging community has been described as something that "gives us a sense of belonging and enables us to support continual growth of each other and ourselves¹." A community can be incredible for igniting a passion for an activity or fostering motivation when motivation is lacking.

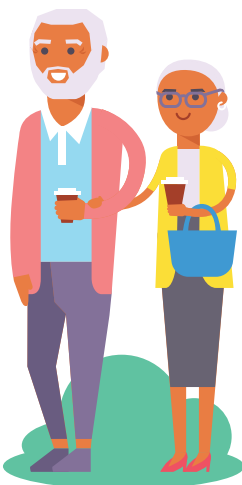
The connections that form between clients/peers create meaningful and lasting friendships that promote motivation and sustainable action that help you live well and manage your Parkinson's. For example, our **Social Singing Program** has been regarded as *"the highlight of my week! It gives me something to look forward to where I can spend an hour and a half singing to some of my favourite songs with some of my favourite people"*.

Our **Thinking, Memory, and Concentration Program** is another example of a program that has allowed our clients to work on their cognition, stay motivated and connect with other people. One client shared their thoughts on the program by saying, *"thank you for creating such a comprehensive variety of activities to assist us in maintaining and improving our memory skills. We looked forward every week to visiting with you and all the other participants"*.

While these are just two examples out of many, they do a magnificent job of showcasing the importance of our active programming. They highlight the subtle but essential aspects that make them beneficial to any routine. You, as our client, are at the heart of why we do what we do, which is why we are excited to offer our programs both in-person and on-line to ensure they are accessible to anyone who wants to get or stay active. To learn more about the physical, cognitive, social, or voice/speech active programs we run, connect with your local Client Services Coordinator.

References

¹ Clarabut, J. (2020, July 23). *The Importance of Community. Wellbeing People.* <https://www.wellbeingpeople.com/2020/07/23/the-importance-of-an-engaging-community/>



NEW PROGRAMS

Parkinson's 101 (begins in January)

This 90-minute program includes a presentation and a Q&A session where you can ask any question you might have regarding Parkinson's in a safe and friendly environment. Designed for those who have recently been or have a loved one who has been diagnosed with Parkinson's, this program takes place the last Thursday evening of every month.

Occupational Therapy Programs (begins in January)

As Parkinson's progresses, activities that were once easy to perform can become much more challenging. Occupational therapy (OT) focuses on helping clients to maintain a sense of independence and continue participating in activities they find meaningful (or fun!). This program will offer individual assessment and interventions to PAA clients both in-person (Edmonton) and on-line. 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 to offer this program.

Care Partner Support Program (begins in March)

This seven-session program aims to help Care Partners navigate their Parkinson's journey, prevent burnout, connect with support and resources, provide connections with other Care Partners, and provide a safe and supportive space to share and discuss their struggles, emotions, and journey in a confidential environment.

Transition to CARE (begins in March)

Caring for a loved one with Parkinson's does not stop when they begin to require more specialized support and you are no longer the primary caregiver; but it does begin to look and feel different. This program will help you make better sense of these changes, stay connected to your loved one, develop strategies to help navigate the transition, and advocate for your loved one in LTC.

Ambiguous Loss & Grief (begins in March)

Nobody plans to get Parkinson's, so it is normal and natural for individuals and families to associate the diagnosis with loss (loss of the future you had planned for, loss of health, etc) and experience grief. This program, for both people with Parkinson's and their Care Partners, is designed to help you understand those feelings and provide you with coping strategies through a series of teachings, discussions, and real world applications of what you have learned.

*To register or put your name on a waiting list for upcoming programs please contact your regional Client Services Coordinator, call us toll-free at **1-800-561-1911**, or email us at info@parkinsonassociation.ca.*

Be sure to include your name, phone number and program you are interested in in the body of the email.



REMINDER

- » To participate in any PAA in-person programming (1:1/family support, support groups, exercise and/or voice programs) Proof (official AHS vaccination documents/ QR code) of full COVID-19 vaccinations (received at least 14 days prior to the event/activity) **OR** a negative COVID-19 test result from an approved testing provider taken within 48 hours of the event/activity will need to be shown in order to attend
- » Advance registration is **required** each month for every Support Group. We have had a few people who hadn't registered show up to Support Group venues where the group had been canceled or moved on-line due to lack of registrants or weather. Registering for Groups in advance ensures that groups are not canceled AND provides us a list of people to call in case of a cancellation or location change. Thank you for your cooperation with this!!



Important Dates to Remember

All PAA Offices will be closed on the following dates:
February 21
 (Family Day) and
April 15 & 18 (Easter)



We're Here as Long as You Need

Supporting Widow's and Widower's

By: Declan Beddow

Earlier this year Parkinson Association of Alberta (PAA) offered our first support program directly aimed at helping widow and widowers who had lost their Person with Parkinson's. The aim of this program is to provide support and education relating to the grief that surrounds the loss of one's partner. Long-time PAA clients Della, Karen, and Rita all participated in the program, and agreed to share their perspective of this unique new Care Partner program. This is what they had to say: *The quotes have been modified for brevity.



What was your experience with the Widows program?

Rita: *I felt like when I was expressing my feelings that people understood what I did or what I was talking about. I never felt judged, and I thought that was very important. I live in a 55+ and a few people have lost their loved ones in the last year here. And they have no help. They just have nobody to talk to except their kids, and when you talk to your kids, they feel like they've got to fix it. And I never felt like, when I was talking at these groups, that you were going to fix it. You were just going to listen to me and that was very good for me. I hope that it'll carry on forever.*

Why was it important to start a widow's program for Parkinson's specifically?

Della: *It is not because the person has passed, that they are no longer here, they are still a big part of our lives. It's a natural progression that we could have a group like this*

to continue to help us grieve and remember our loved ones and speak with people who understand our journey. Because, yes, there are a lot of other support groups and a lot of other grief counselling, and even though everyone's Parkinson's journey was different there are a lot of shared experiences. As Rita said, nobody fixed anything for me, but just listening and sharing did help me through a lot of decisions and a lot of tough times. So, it's just a natural progression that we should continue to care for and help each other along with this.

Karen: *I think it is a great comfort in everyone being in the same boat as we have all been through the Parkinson's journey. If you've experienced another grieving group, which I did once - I went to one meeting, and no one there could really understand what the other person was going through except that we were grieving the loss of a loved one which is extremely traumatic on its own. But, with the Parkinson's grieving group, we've all walked the same journey, we're all in the same boat, and it's very much a comfort to me to speak to others who are in the same situation as I am and know exactly what you're going through.*

Rita: *I think I can pretty well say ditto on both Della and Karen's points. I just feel like when you get down - we look forward to our meetings. You know what date it's going to be and I knew I was going to be having some support when that date came. And the feeling of not being alone. You can be down today, and you get into a meeting and if others have made it, you can make it. You feel like you fit in.*

We're Here as Long as You Need

Supporting Widow's and Widower's

What do you think the most valuable aspect of the program is?

Della: *I always appreciated the fact that you would present articles for us, food for thought, and I found those wonderful jumping off points. It wasn't structure that "This is what you have to talk about today." If something came up for somebody it was so open and welcoming and non-judgemental. We could all just identify with what they were saying and help them. And I found that very rewarding, because we were all caregivers and we were all in that position so long, there is kind of an emptiness afterwards. If there was anything, I ever said that was able to help somebody for two minutes then I felt really nice about that. It's great that I was able to say that and help someone, and vice versa anything that the group said that resonated with me was very valuable. So, that's what I got from it, camaraderie, sharing and feeling like I'm not alone, I've not been abandoned.*

Karen: *I've had people comment when I tell them I'm with the widow's group, and they say they have had nothing. Except friends that don't really know how to react, if they haven't gone through it, or your children and they do want to fix it, quickly. They are very lonely if they haven't got a connection with others in the same situation. So, I feel very fortunate and very blessed that we have got this group.*

What would you say to someone who is considering participating in the next round of the program?

Karen: *Go! and if you need someone to come with you, let me know.*

Rita: *I think the feeling that all three of us seemed to have experienced is that we were able to share our experiences and our hope, and that when you see someone who has lost their loved one, and it's been six months, and they can smile off and on, that's a good sign.*

Della: *It may seem very overwhelming and scary, but through out my life I have found that if you just open yourself up to these experiences, be vulnerable, and express yourself, that you can gain an awful lot. You really can gain new friendships, gain insights, gain understanding of your self in many ways, and how to carry on. You don't have to go through this alone.*

Thank you, ladies!

— ○ — ○ — ○ —

The Widow's and Widower's program will be an important part of the support services provided by PAA going forward. As you have heard from Della, Karen, and Rita, it is extremely valuable support system for anyone who has lost their Person with Parkinson's. I

also want to emphasize that this program is not just for people who have lost their spouse recently. Due to the sensitive nature of this program, we don't have any "set schedule" for when it will run next, rather when we have enough people who have indicated they would like to participate we will begin another session. If you are a widow or widower who feels like you could use some support or would like to participate in the next round of the program, please reach out to your Client Services Coordinator or call us toll-free at **1-800-561-1911**.

Thank you to Della, Karen, and Rita for agreeing to be a part of this article and sharing your experiences with us.





Support Groups

Feel Empowered & Supported

By: *Sherry Bower-Gagne*

When you are facing a diagnosis of Parkinson disease (be it as the person diagnosed or a loved one), it is important to know you don't have to walk the path alone. No matter where you are in your journey, Parkinson Association of Alberta's Support Groups bring people together who are going through or have gone through similar experiences.

Support groups provide the opportunity for people to share their experiences, coping strategies, and firsthand knowledge. You are the experts on your disease, support groups help create the opening to learn from each other.

Larry and Lorna Garnier who have a family farm near Clandonald (80 kilometres north/west of Lloydminster) began attending the Lloydminster support group three years ago. Larry shares that

“Coming to support groups has changed my life. People know what I am going through. They get it.”

Support groups are where new relationships are built, laughter is shared, and life can take on a new light.

Parkinson Association of Alberta's Client Services Team facilitate over 40 support groups across Alberta. No matter where you are, we are here, and you can connect with us and others. The majority of our Support Groups are General Parkinson's groups. These groups provide a welcoming atmosphere where you can learn more about Parkinson disease from knowledgeable facilitators and your peers. In addition to the General

Parkinson's Support Groups, we offer a variety that are more specific. It is a priority for us to ensure that everyone feels supported, wherever you live, and whatever your diagnosis or treatment may be. Whether you are newly diagnosed, diagnosed with young onset (under 55), Parkinson's plus, or have had the surgical treatments DBS or Duodopa, there are specific groups just for you. You are welcome to join your peers in person, through ZOOM or by phone from anywhere! We believe “knowledge is power,” and we want you to feel empowered.

Loved ones and Care Partners please know that we understand that a diagnosis of Parkinson disease affects the entire family. While it is true that one person physically receives the diagnosis; it can have a tremendous impact on the care partner and family. We are also here for you, we want to provide a supportive network that will be a safe place to ask questions, share thoughts, and find understanding among your peers and very likely some laughter. Care Partner support groups meet once a month and all Care Partners are welcome.

For those who have lost a loved one with Parkinson's, we understand that losing a partner is one of the most devastating things a person can experience. Please know that you are not alone, we are here to support you, as a compliment to our Widow/Widowers Program (see page 10) we offer a follow-up support group once a month. You started your Parkinson journey with us, we will be here for you as long as you need us.

Please remember, no matter where you are, or what you are dealing with, we are here. Give us a call and let us find a support group that works for you.

REMINDER: Advance registration is **required** every month, and for every support group you wish to attend. This is vital to ensuring we can follow COVID protocols and contact you in the case of a cancellation, location change, or switch to an online Zoom meeting. **Support groups will not run if no registrations have been received.** Please note that Support Groups will not run on statutory holidays. To register, please call toll-free **1-800-561-1911** or, talk to your Client Services Coordinator.

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

EDMONTON REGION...continued	780-425-6400
SHERWOOD PARK	
2nd Tuesday	1:00PM
ST ALBERT	
3rd Tuesday	10:00AM
WESTLOCK	
3rd Thursday (Zoom / Call-in)	10:00AM
WHITECOURT	
3rd Thursday (Zoom / Call-in)	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 (New Time)	2:00PM
SOUTHERN ALBERTA	
2nd Thursday (Zoom / Call-in)	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 Thursday (New Day & Time) (Zoom / Call-in)	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 (Zoom / Call-in)	10:00AM

The More You Know

Education Programs

By: Colleen Davison



There are so many ways to learn more about the different aspects of Parkinson disease and Parkinson's Plus Syndromes. From information on the disease itself, to research, to topics that cover the various ways to live well, and so much more. Our Education Programs and resources help you gain knowledge and understanding and apply what you have learned in your daily life. These programs currently include:

Information and Resources

We are pleased to offer our information and resources in both printed and downloadable online format. Documents and booklets include disease-specific information on Parkinson disease and Parkinson's Plus Syndromes, information on different aspects of life with Parkinson's (ie: care partners, driving, adaptive tools, stress-management) and streamlined access (via Client Services Coordinator) to community and government resources. Client Services Coordinators provide printed materials in a variety of

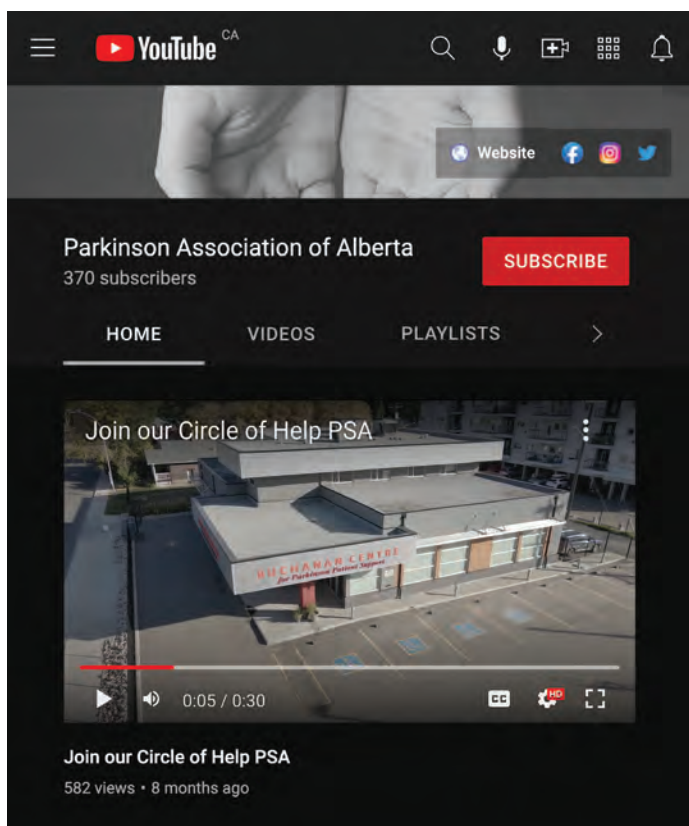
ways: at one-on-one/family support sessions, support groups, presentations and can even mail them directly to you. We also continue to add to our catalogue of knowledge and resources as new information becomes available. Our information is available anytime by visiting our website's **RESOURCES** tab.

Webinar Wednesdays

We host a wide variety of Webinars throughout the year so we can offer safe, reliable information delivered directly into your home. We are proud to have well established working relationships with

regional, provincial, national, and international experts in a variety of fields including (but not limited to): movement disorders, neurology, neurosurgery, pharmacists, mental health, housing and home care, driving, physiotherapy, and so much more! Our Webinar Wednesday speakers answer your questions in real time, providing a valuable take away that is unique to you and important for all! Can't make it to the live presentation? Each Webinar is uploaded to our Parkinson Association of Alberta YouTube channel for ease of access and refresher information anytime!





YouTube Channel

Did you know Parkinson Association of Alberta has our own YouTube Channel? Our channel contains a variety of videos to help you learn more about and live well with Parkinson's. From past Webinar Wednesday speakers, to our Motivational Monday exercise videos, and interviews and testimonials from clients, our channel is a great way to get educated and stay active! You can make your way there with ease simply by going to the very bottom on our website homepage and clicking on the YouTube icon.

Parkinson Pulse Magazine

Since you are reading this article, you are likely already fairly familiar with Pulse; but for those who may be new to the magazine I'll provide a little insight. Parkinson Pulse is our quarterly magazine, with issues available in Winter (January), Spring (April), Summer (July), and Fall (October). It is a means to keep the Parkinson's community in Alberta and beyond educated on Parkinson's information pertaining to health, well-being, and quality of life; as well as up-to-date information on new programs, events and opportunities.



Hope Conference

Hope Conference is Alberta's largest conference on Parkinson disease. It is an opportunity for people to come together to learn from regional, national and international experts, find out more about Parkinson disease, and learn practical tips and tools for living better with Parkinson's. With a partnership from Brain Canada we were able to transition Hope Conference to an online platform; and deliver it at no cost to attendees! This transition made it easier for people from across Alberta and Canada to join and helped double participation to 300+!

Parkinson's 101 Program *(launching January 2022)*

Receiving a Parkinson's diagnosis can be overwhelming for both the individual and their family. It can take time to wrap one's head around the news they just received, and you might not have all your questions answered at that particular medical appointment. This is where we come in. We invite you to join us at our new Parkinson's 101 Program taking place on the last Thursday of every month (except December) from 6:30PM – 8:00PM. This online program will help those individuals who have been recently diagnosed and their families learn more about Parkinson disease and ask any questions they might have in a friendly and safe space. Call us toll-free at **1-800-561-1911** to register.

Aware in Care Self-Advocacy Kit

The Aware in Care Kit is a useful tool to help people advocate for themselves and/or a loved one in unplanned and planned hospital/healthcare settings. This kit is distributed as part of a collaboration with the Parkinson's Foundation and is given at no charge to Members (one time) and for a nominal fee for non-members.



Outreach Programs

Stronger Together

By: **Emma Torneiro**

Do you remember how you first heard about Parkinson Association of Alberta? Was it through your community neurologist, your general practitioner (GP), referral from community resources or advertisements in your community? Maybe you received a blue package of information about Parkinson disease and our organization.

This is one aspect of our Organization's outreach! The main goal of our Outreach Programs, similar to many of our other services, is to provide knowledge and support to our growing Parkinson's community. Our outreach is achieved through the creation of stakeholder partnerships, sharing Parkinson's information through presentations and printed materials, expanding our Team's knowledge and advocacy for our clients.

Stakeholders

Our community stakeholders are an essential part of our Parkinson community! Our engagement and relationships with stakeholders help us ensure that YOU have access to the best support and resources for you, regardless of geographical location. We are continuously engaging with and expanding our knowledge of community stakeholders and the services they offer that may be beneficial to our clients. We focus on creating vital partnerships within the communities where our clients live to provide information, programs, services and supports in the most accessible

and beneficial way. Our current stakeholders include (but are not limited to) health care professionals, program partners, community service organizations and recreation facilities, government agencies, home care agencies and local businesses, etc. Our program partners have shared they

"love to help the Parkinson community, love seeing people get active and are filled with love from the community".



Presentations & In-Services

Can you imagine a world where people impacted by Parkinson disease have easy access to Parkinson related information and health care professionals are educated on Parkinson's? We can!

Parkinson Association of Alberta's Outreach includes educational presentations and in-services to the general public, health care professionals, long term facilities, home care companies, and post-secondary students just to name a few. Our presentations are aimed at those members of the general public who have or who has a loved one who has Parkinson's; but may not be aware that help and support are available.

Our in-services on the other hand, are aimed at those in the community who want to know more about Parkinson disease as it pertains to their industry and/or education. These tailored presentations are typically delivered to staff at Long Term Care Facilities, Home Care organizations, post secondary institutions, mental health professionals, massage schools, etc. Our post-secondary institutions have shared

"the presentations aid the students' learning and knowledge about Parkinson's and how Parkinson Association of Alberta is a resource for those impacted by the disease".

Our Team strongly believes in sharing knowledge to better support our community.

Printed Collateral

When searching for information on Parkinson disease or Parkinson Plus syndromes, there's never-ending resources available (thanks, Dr. Google!). It can often be overwhelming and stressful to sift through the information to determine what is important, valuable, or even truthful when it comes to Parkinson's information. That's where we come in! The education aspect of our outreach attempts to ease the stress by providing easily accessible and understandable information to you and our community stakeholders. Parkinson's information is also available through our quarterly Pulse magazines, crafted specifically for

our clients' needs with articles based on common concerns or questions that arise with Parkinson's or Parkinson's Plus. We make our printed collateral available online, through our Client Services Coordinators, and by dropping off magazines, booklets and brochures at clinics and other locations in communities across Alberta. *Interested in having information distributed to a location near you? Contact our Client Services Team at 1-800-561-1911.*

Knowledge Base Expansion

Our provincial Client Services Team is always looking to learn more and engaging in ongoing education to better support you. Whether it is a talk and Q&A session from an expert, an online course or self-directed research we embody a "know better and do better" philosophy. For example, over the course of the pandemic our Team researched and studied advanced care planning, Mental Health First Aid, and Federal and Provincial government benefits so we are better positioned to share that knowledge and expertise with you!

Advocacy

As you hopefully already know, our main goal at Parkinson Association of Alberta is providing support to you and your loved ones impacted by the disease. The supports can be as unique to you as your Parkinson's and available throughout the progression of the disease. The support can include advocacy for yourself or your loved one with PD. As an organization, we strive towards community awareness and advocacy for Parkinson's and Parkinson Plus Syndromes. Our current efforts in advocacy include collaborating with national and international Parkinson organizations, such as PD Avengers, Brain Canada, and Parkinson Canada.

Innovation & Inspiration

Research for Today and Tomorrow

By: **Brandi La Bonte**

For thousands of years people have been living with and families have been affected by Parkinson disease. It is only since the 1960s however, that significant strides began to take place to help alleviate the symptoms and improve quality of life. For only a few short decades, research in Parkinson disease (worldwide) has been instrumental in finding new treatments to address symptoms of Parkinson's, understand pathophysiology, and improve quality of life. Levodopa, dopamine agonists, deep brain stimulation, Duodopa, exercise and other complementary therapies are just some of the many positive and impactful outcomes of Parkinson's research throughout the last 60 years.

Research is the key to a better and brighter future in Parkinson disease and Parkinson's Plus Syndromes.

Research, of course, into a cause and cure; but also, into aspects that will help people live well with the disease right now. New medications, new ways to deliver treatment, new understandings of non-motor symptoms like cognitive function and depression, or new ways to approach life with Parkinson's are just a portion of the research that is being undertaken.

In addition to helping fund research right here in Alberta, Parkinson Association of Alberta is dedicated to promoting research and opportunities for you to participate in research trials. Not only do we need to enhance and encourage research in Parkinson disease, but we need to encourage participation in research trial opportunities. (Did you know that after funding, lack of participation in trials is the biggest hurdle for researchers?!?)

Are you interested in participating in a research trial, but aren't sure where to start, or think you live too far away from a major center to have an impact? The good news is our website lists a variety of ongoing research trials available for both people with Parkinson's and/or Care Partners – and while some of them require a visit to one of our major universities, many can be done via an on-line survey or telephone call!! To find out more visit the **"Participate in Research"** section of our website which is located under the **GET INVOLVED** tab.

We are also excited to shine a light on the incredible work being done for Parkinson's by researchers right here in Alberta. You can read stories and testimonials from Alberta researchers (including Dr. Jennifer Andrews, Dr. Nick Strzalkowski, and more) in the "News" section of our website which is located in under the **OUR IMPACT** tab.



Announcing our updated Membership Structure for 2022

Join our safe and caring community of support!



As we work to bring help and hope to the growing number of Albertan's living with or loving somebody with Parkinson disease and Parkinson Plus Syndromes, we are guided by the needs of those we have the privilege of working with. By becoming a member, you can influence the direction and impact of our efforts.

We have updated our membership structure with you in mind:

Benefits of Membership: In addition to the important voting privilege that guides the direction of Parkinson Association of Alberta, the following benefits are also included.

Primary Membership \$35	Secondary Membership \$15
Voting Member Card with Medical Alert information	Voting Member Card
Reduced pricing for programs and events	Reduced pricing for programs and events
Aware-In-Care Kit	(By request)
Mailed copy of Pulse, PAA's Quarterly Magazine	X
Program and event updates direct to your inbox	Program and event updates direct to your inbox

A **Primary Membership** of \$35 per year and **Secondary Memberships** of \$15 per year can be purchased over the phone, online, or through your local PAA staff.



Call us today at **1-800-561-1911**

NOTE: The above represents a change to our previous membership structure and reflects the feedback of our active members. **Secondary memberships may only be purchased adjacent to a primary membership** and may extend to multiple family members and friends of the primary membership holder. Should you have any questions or comments regarding the change in structure, please do not hesitate to contact us toll-free at **1-800-561-1911**.

☐ **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 updates from PAA: email news, Pulse Magazine by email **YES NO**I would like my Pulse Magazine mailed to me **YES NO**I would like to learn more about volunteering **YES NO**I want a staff member to contact me about PD and/or PD+ **YES NO**I want a staff member to contact me about Programs and Services **YES NO**

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

☐ **ADDITIONAL \$15 Secondary Membership**

Name: _____ Email: _____

Address: _____

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

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**



Sign up for our Newsletter

Sign up to receive updates on our programs and support groups, research news, events and more delivered to your inbox.

E-mail

SIGN UP

parkinsonassociation.ca



There are over 10,000 people in Alberta living with Parkinson disease and Parkinson Plus Syndromes.

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

**HELP
MAKE A
DIFFERENCE**

DONATE



 **Parkinson**
Association of Alberta

parkinsonassociation.ca