


Parkinson PULSE

Connecting people living with Parkinson disease in Alberta



*In this
Together...*

**The Care
Partner Issue**



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Fall 2020

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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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“It’s not how much you do, but how much love you put in the doing.”

– *Mother Theresa*

One of the most wonderful, and the most difficult, parts of life is the privilege of caring for someone else. Whether as a parent, a partner or a friend, watching a person we love go through challenges and changes can be extremely difficult. It can also be filled with humour, meaning, memories and rewarding moments of love and inspiration.

November is National Family Caregivers Month and so we are dedicating this edition of Parkinson Pulse to the thousands of care partners and caregivers across Alberta who are living life with Parkinson’s alongside their loved ones. You are often the voice, the motivation, the driver and the navigator. We are honoured to have you as part of our community and provide any measure of support we can, when you need it. On page 17, you will find a list of opportunities to join a Care Partner Support group. While some of our groups have returned to in-person with restrictions, all virtual groups are available to you regardless of where you are in the province.

On page 4, there’s a mention of asking for help. I recently had a conversation with a colleague about this exact thing. Quite often we don’t ask for help because we don’t want to be a bother. Here’s a thing I’ve learned. People want to help. Helping makes us feel good and often better than we might have felt without offering or providing support. You are not a bother. You are a lone individual who, despite your best efforts, simply can’t always do and be everything. By asking for help, you are involving other family members and friends (and

sometimes our amazing Client Services Coordinators here at PAA) in finding a solution to a problem. This makes people feel useful, valued and involved.

Speaking of involved. We are so pleased to be bringing a virtual version of our Hope Conference to your living room on November 28th. While the lineup is not quite set, we are confident our guests from across the country will bring meaningful, supportive and informative content. Watch for details on our website and the weekend e-blasts.

As we do not have another edition of Pulse before the new year, I’d like to take this opportunity to thank you for your generous commitment to our Parkinson’s community and to each other. All of us at PAA wish you a peaceful and warm holiday season.

Sincerely,

Lana Tordoff,
Chief Executive Officer

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Parkinson's 101 for Care Partners

Written by: Brandi La Bonte



Parkinson disease affects the entire family. While it is, of course, true that only one person physically receives the diagnosis; the ripple effect created can have a tremendous impact on the care partner (and family).

What do Care Partners (and Family Members) need to Know about Parkinson disease?

Parkinson's is different for everyone

Like fingerprints or tiger stripes, the way a person diagnosed with Parkinson's experiences symptoms or progresses varies significantly from person to person. While there are common symptoms that many people with Parkinson's will experience, no two cases are the same. It is important not to compare your loved one to others you may know/meet with Parkinson disease. It is equally important to communicate with your loved one to gauge the ways they might be affected.

Many of the symptoms are invisible

Many of the symptoms of Parkinson's are invisible. Signs of depression, fatigue and anxiety, for example, might not be immediately apparent, but your loved one may be suffering inside. It is important to encourage your loved one to be open and honest (in a respectful manner) about how they feel and the progression of their 'invisible' symptoms.

Help your loved one maintain their independence for as long as safe and possible

As your loved one's Parkinson's progresses, their independence and/or options become more limited. If your loved one is able to perform certain activities, such as cooking meals, walking the dog or putting on a coat, then encourage him/her to do so even though it may take a little more time. It is also beneficial to talk about the future (finances, driving, living situations, etc) early on and at periodic intervals to help maintain a feeling of independence and personal choice when options begin to become limited.

Top 4 Tips for Care Partners

1. Work Together

Work with your loved one to maintain a care partnership. Caring within families should always be a two-way street — so that you and your loved one with Parkinson's are each able to give and receive support from the other, even when the Parkinson's becomes more disabling.

2. Get Support

Care partners (and families) do not need to face a Parkinson's diagnosis alone. Having a support system can give you a boost in meeting challenges and make you feel less alone in your role. Reach out to family, friends and the community for support. Seek help when/if you need it, and create a strong support network for your entire family.

3. Ask for Help

No one can read your mind, and most people don't want to risk offending you by suggesting you need help. The best strategy when asking for help is to be specific. Instead of saying to your relative, friend, or neighbor, "I really need some help," try "I'd like to get out and do some errands on Tuesday – could you keep Alice company from 2-3 so I don't have to worry about leaving her alone?" Most people are happy to help when they know what you need.

4. Take Care of Yourself

Remember that your physical and emotional health is just as important as your loved ones'. The care partner role can be both demanding and draining at times, and we know that care partners tend to neglect their own health while caring for the other person.

Parkinson Association of Alberta's Client Services Coordinators are there to help care partners navigate their way through the ups and downs of caring for a loved one, maintain their sense of identity, and manage their own self-care through a variety of support options including support groups, one-on-one support, education and other activities.



Please note Parkinson Association Offices will be closed December 24, 2020 through January 3, 2021 for our annual winter break.

We will return to regular operating hours on Monday, January 4, 2021



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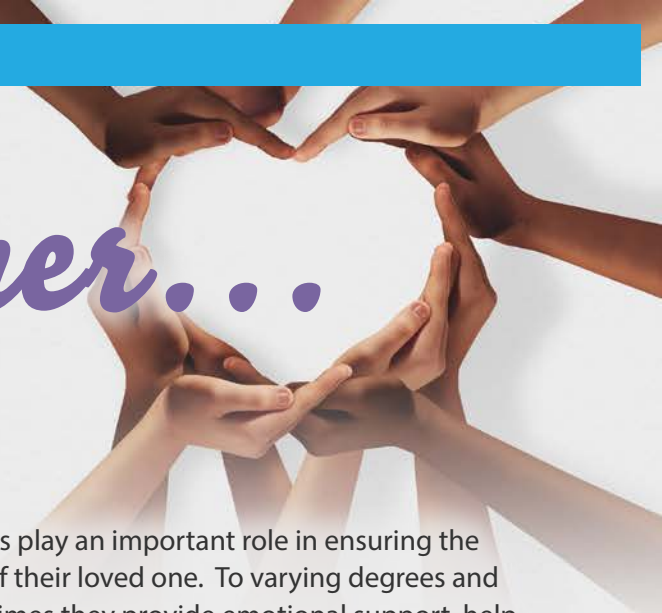
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In this Together...

The Care Partner Issue

Written By: **Brandi La Bonte**



By the time you read this I will be wrapping up my 10th year with Parkinson Association of Alberta and heading into my 11th. The past eight months during the lockdown and subsequent COVID weirdness gave me plenty of time to reflect on these past 10 years. As I reflected on my time here, what I've accomplished, and what I still wanted to achieve, one thing became glaringly obvious. What was it you might wonder? Well, after 10 years, and over 30 issues of the magazine, I had yet to devote an entire issue to the other half of our clients – the Care Partners. Oh sure, over the years I've done or collected articles and stories about and from care partners, but I'd never given this incredible group of humans the attention they too deserve. And that needed to change, and now it has.

As I sit here working on my final piece of this issue – a collection of both new and previously published articles – it is my sincere hope that all (not only the care partners) who read it garner some level of insight and/or gain helpful/useful information. As always I welcome your feedback, comments and insights.

In speaking with many care partners over the years, the top four things you have shared as key advice are:

- » Listen and spend quality time together with your loved one
- » Get informed
- » Accept/ask for help
- » Find your tribe - a group of people – friends, peers who can relate and support you.

Caring for another human being is one of the most incredible acts of love there is. As we get older or a loved one becomes ill or is diagnosed with Parkinson's the level of care required can change. With Parkinson's the need for care typically changes gradually, over time.

Care partners play an important role in ensuring the well-being of their loved one. To varying degrees and at differing times they provide emotional support, help with medications, assistance with physical challenges, and much more. Many caregivers see their role as being an advocate to and for their loved one. They make sure that both the medical care their loved one receives and life decisions that need to be made lines up with their life goals and maintains a good quality of life.

Wait...care partner or a caregiver? Which is it? Honestly the terms are often used interchangeably. To simplify Parkinson Association typically uses Care Partner. There has been some debate over the years on what the "correct" term is. An outreach project for education done at Stanford University came up with this simple, yet clear way to make the distinction.

"The difference is that of a one- versus a two-way street.

A caregiver is someone who provides care for someone who is unable to care for themselves. The term implies a one-way relationship between two people—one gives and the other receives. It suggests that a passive role is taken by the recipient of care.

However, caring is often a two-way street, and this balance of care is more fully captured by the term, care partner. A partnership is characterized by mutual cooperation and joint responsibilities. There are opportunities to give as well as receive by both parties in a care partnership.¹

Whatever term you choose, the journey of a caring for a loved one with Parkinson's can be an emotional rollercoaster. There will be many challenging days; but there will also be beautiful moments of joy and love.

References

- 1 Shin, Linda *Stanford University Care Partner's Guide: Care Partner versus Caregiver* April 2018, <https://hopes.stanford.edu/care-partners-guide-care-partner-versus-caregiver/>

A Care Partner/Caregiver Pledge!

Written By: Family Caregiver Alliance (*with Parkinson Association of Alberta edits)

1. I will understand that I can't care for anyone else if I don't also care for myself. I will keep an image in my mind of putting the oxygen mask on myself first.
2. I will remember that the only person I can change is myself. I cannot change my loved one who is ill, nor my family members or friends.
3. I will find opportunities to laugh, daily. These might come in movies, jokes, television, or with friends who can see the humor in my situation and remind me to do the same.
4. I will get away from my care partnering/caregiving duties on a regular basis, even if it is just to walk around the block. But I will also find ways to have lunch with a friend, go to a movie, window shop, breathe in fresh air, watch the sunset, or eat a hot fudge sundae.
5. I will visit a support group, either online or in person in my community, so that I know I am not alone. If a support group isn't right for me, I will find a friend to talk to, seek professional help, or attend a workshop.
6. I will learn as much as I can about my loved one's illness so I can better care for him or her with understanding. I will learn techniques that will make care partnering/caregiving easier for both of us.
7. I will say "yes" when people offer to help. I will make a list of things they can do and post it on the refrigerator, so that when those offers come, I'll be ready. When there are not offers, I will ask for help, even though it might be hard to do so.
8. I will use community resources—such as Parkinson Association of Alberta programs, Homecare support, Meals on Wheels, adult day programs, and/or other community respite programs—to help make my care partnering/ caregiving duties easier.
9. I will find something I really like to do and make sure I find time to do it on a regular basis. Just because I am a care partner/caregiver doesn't mean I have to give up everything that is meaningful to me. I will read, knit, garden, scrapbook, do woodworking, or watch a movie or sporting event for a designated period of time every week.
10. I will remember that I am loved and appreciated, even when my loved one can't tell me that. I will honor the nurturing, responsibility, caring, and support that I provide to my loved one as a gift I give.

My Story

Parkinson's, Marriage and Caregiving

Written by: **Ian Barnes**

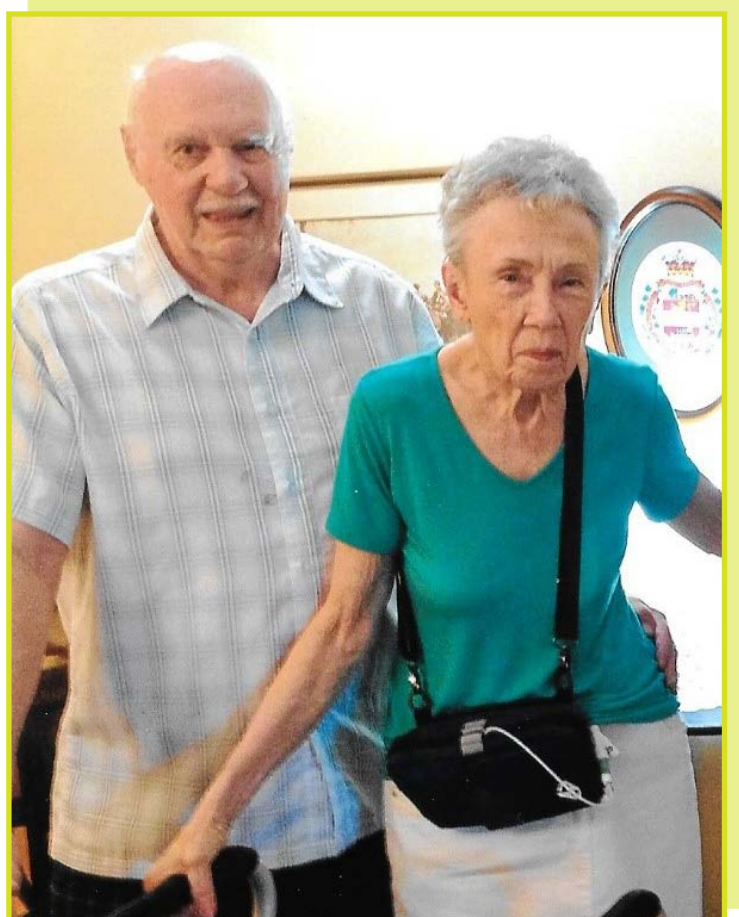
Originally published Summer 2016

Parkinson's is a debilitating disease that, amongst other things, places tremendous pressure on a marriage. How does one cope? In the case of my wife and I, it has been a challenge.

During the early stages of the disease it wasn't much of a problem. Changes were occurring relatively slowly. We were still able to participate in all of our favorite activities. The medication was doing its job and our quality of life was only mildly affected.

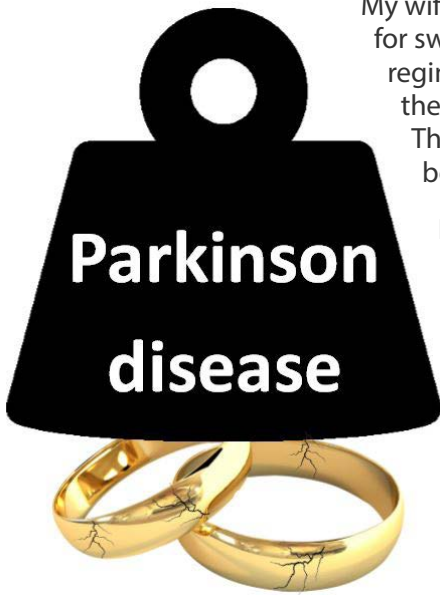
It has now been thirteen years since my wife was first diagnosed with Parkinson's and we sat crying and hugging in our car in the doctor's parking lot vowing that we would not let this disease get the best of us. Since that time major changes have taken place in our lives. My wife's symptoms have increased such that most of the activities we took for granted have been impeded or are no longer possible. Every hour of every day is taken up with managing the disease. Those brave words of thirteen years ago have been and are being severely tested on a daily basis.

Today I am a caregiver (now known as a care partner). A term I refused to accept for many years. I was a husband. I didn't need a label to fulfill that responsibility. Our wedding vows included the words "in sickness and in health." So I told myself to get on with being a good spouse. I didn't need help (I thought) and definitely was not about to join any organization. But as time went on I began to notice my own personality changing. I began to feel resentment because my life had changed. There were so many things I couldn't do anymore. This however made me feel terribly guilty. Who was I to be complaining? I wasn't the one with Parkinson's. I found myself becoming angry. Angry because the medical system wasn't doing enough for my wife. Why did it take so long to see a specialist? Why couldn't I help my wife when she cried from pain and frustration? I began to admonish myself because I wasn't doing a very good job of comforting my wife when she needed love and kindness to comfort her. Whatever I tried didn't seem to help.



Fortunately, Parkinson Association was there in Edmonton with staff and a number of programs for those suffering with the disease. We started joining every program we could. It was a godsend to us and gave my wife a sense of purpose and belonging. One of the programs they offered was COMPASS which was geared specifically to caregivers/care partners. I was reluctantly convinced into going by my wife and some of the staff at the Parkinson's Office. I had been taking my wife to the various programs offered for her, but sitting quietly in the corner reading a book. So I went to one of the sessions. I felt uncomfortable and didn't want to go back the next week. Again I was pushed into going. Then, as I listened to the Client Services Coordinator and other attendees I learned that I was not alone, the thoughts I had, others did as well.

In spite of all this, even with the sense of purpose provided by the many programs, something was happening to our marriage. The love and sweetness that had existed for so many years seemed to be disappearing. We began to argue over the slightest thing. One day at our support group meeting another care partner said, "All I seem to do is nag." Suddenly I realized that was exactly what I was doing. "You didn't take your pills." "Did you do your exercises?" "Did you drink your six glasses of water?" "Speak up, I can't hear you." And on and on and on. I knew this was definitely happening in our marriage.



My wife and I were so busy trying to cope with the symptoms that we have little time for sweet, cuddly moments anymore. We were busy trying to deal with the medication regime seven times a day, the on/off periods, the anxiety attacks, the dyskinesia and the stiffness. The accompanying pain that makes walking difficult if not impossible. The disease was wearing us out. Even the normal 'please and thank you's' exchanged between loved ones had gone. No wonder strains had appeared in our relationship.

I no longer leave my wife alone. Going anywhere or doing anything or leaving her for a second brings on an anxiety attack. We are trying to cope with this.

We have seen a Parkinson's psychiatrist who is trying to help us. Unfortunately the medication he has prescribed us has caused her terrible side effects and now we are trying to cope with that. Thank heavens for our daughter, condo neighbors, friends and our church. They have all been a blessing to us.

The counsellor at the COMPASS program as well as friends told me I should put myself first and take respite every once in a while. I know they are right. And while it is all well and good for the care partner to take respite; I still worry about my poor wife who is suffering with Parkinson's. Where does she go for respite? It makes me weep inside when she asks, "Why me God, what did I do to deserve this?" Or when she cries out "I don't want to live like this anymore."

Thank heavens there are still some good times, when the medication is working and each day we carefully coordinate our activities to coincide with those times. They are few and far between, but they are still a blessing. It has taken all of our braveness to carry on along our journey with this disease. And, in spite of the many difficulties we are still determined not to give in.

Tips for Dealing with Parkinson Disease as a Couple

- 1. Communication** – Communication is important in relationships, not only do couples need to talk openly, but also commit to being good listeners. No matter how well you know and love each other, you cannot read each other's mind. Communicating clearly and listening actively will help couples move forward in a positive, unified manner and avoid misunderstandings that may cause hurt & anger.
- 2. Continue to make intimacy a priority** – Physical intimacy is one of the greatest tangible bonds between couples. There are many forms and levels of intimacy and all of them impact the strength, commitment and fulfillment of relationships. From a physical intimacy perspective, half of people with Parkinson's experience some form of sexual dysfunction; so it is important to talk not only to your partner, but to your doctor openly and honestly as help is available.
- 3. Enjoy togetherness, but encourage/maintain independence** – Parkinson's is a progressive disease, and the progression will at varying points impact your/your loved one's independence. Encouraging/maintaining independence in physical tasks (so long as it remains safe), speaking and decision making is key to preserving a sense-of self and accomplishment.
- 4. Accept offers of help** – Accepting help does not mean you are weak or admitting you cannot "handle" the situation. It's actually quite the opposite. Whether it is an offer to watch the kids, bring over a casserole or shovel the driveway...a little help can alleviate some of the day-to-day stresses of life and free up some time for the two of you!



Keeping the Lines of Communication Open

Written by: **Brandi La Bonte**

Open, honest communication is a part of every healthy relationship. Unfortunately, as Parkinson's progresses communication is one of the key areas affected. Voice and speech problems, deteriorating facial expressions and cognitive issues all contribute to communication challenges. This can lend itself to a situation where both parties have the desire to communicate but their abilities simply do not align.

The good news is there are things you can do as a care partner/family member of a person with Parkinson disease to improve communication and decrease stress.

If you're speaking to someone who has Parkinson's disease, keep these tips in mind:

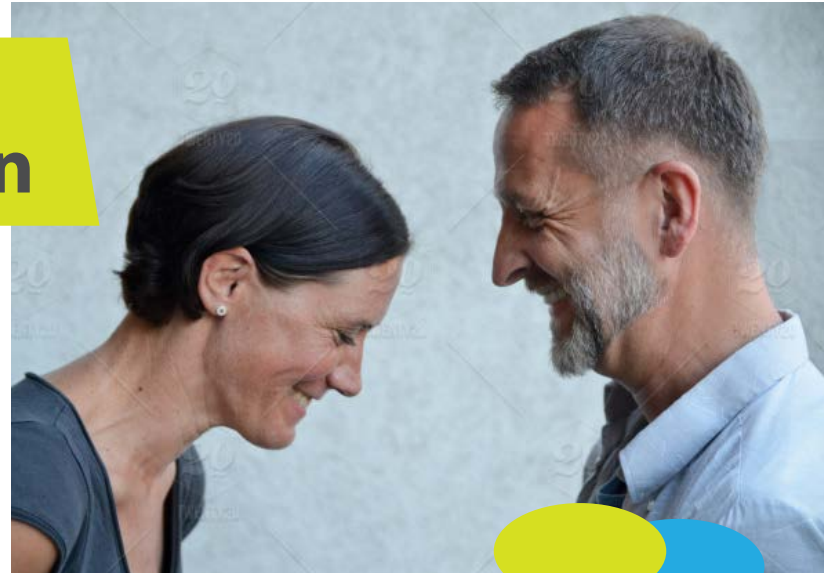
- » Be patient, speak clearly and calmly and allow enough time for your loved one to reply.
- » Create a positive atmosphere. Hold conversations at eye level and make eye contact during conversation. Sit down if the person with Parkinson's is sitting and assume a relaxed posture to convey your patience and willingness to listen.
- » Limit distractions and noise – including tv, radio, cell phones and too many people in the room.
- » Support and reassure your loved one throughout the conversation. Give feedback such as a nod of the head or a "yes" or "I see" to indicate that you understand what he/she is saying.
- » Do not say you understand when you really don't. Repeat any part of the statement you did understand and ask for clarification or repetition of the rest. Asking for a repetition of a phrase may result in clearer pronunciation the second time around.
- » If you cannot understand what was said, ask the person for clarification or to repeat; if you pretend to understand in order to save time, misunderstandings can result. Also, the person with Parkinson's may not make as much of an effort to speak clearly if he/she thinks you understand.
- » Avoid finishing sentences for someone with Parkinson's unless asked for help finding a word or phrase.
- » Ask questions that:
 - require yes/no answers. *ie:* instead of asking, "What would you like to eat?" ask, "Would you like pancakes?"
 - offer two choices when you ask a question. *ie:* "Would you like soup or a sandwich for lunch?"
- » Use gentle prompts before beginning a new topic of conversation. *ie:* "Let's talk about the kids." And, when you change the subject, use similar cues *ie:* "Let's talk about the garden now".

As Parkinson's progresses there may come a time when cognitive issues present a larger problem and verbal communication is no longer ideal or possible. This can be especially difficult for both parties. A few things to remember:

- » Do not assume your loved one cannot understand what is being said. Never say anything you would not want your loved one to hear.
- » The power of human touch is undeniable. Human touch has long been known to have soothing, healing qualities, especially for those who are unable to communicate using traditional methods.
- » Look for subtle changes in behavior, breathing and posture to see what you should continue or what you should change.



Communicating isn't always easy; and when your loved one has Parkinson's it can be even more difficult. While your approach to communication will need to change as the disease progresses, there are ways to help you maintain open lines of communication with your loved one. It just takes patience and practice.





Care Partner Dilemma: Exercise or Rest?

Written by: *Tara Chisholm, MA*

Exercise or rest? How can I exercise when I have been lifting, transferring, cooking, cleaning and driving around all day? I have already done my fair share of moving for today, haven't I? These are common questions that sometimes float through the minds of caregivers/care partners of individuals with Parkinson disease. Of the two options, exercise or rest, research shows that exercise is the far better choice. It may prevent you from getting sick, give you more energy and even help you to sleep better when you do get to lay your head down.

Statistics Canada discovered that among those who received assistance because of Parkinson disease, 84% relied at least in part on family, friends or neighbours. For the most part, the recipient's spouse was found to be the main caregiver (64%). These informal caregivers, defined as unpaid caregivers by Statistics Canada, may find themselves performing tasks that are more physically or mentally demanding than before their loved one's diagnosis. Exercise is known to help reduce stress and boost mood which can not only make your life better, but also the lives of those you care for.

Exercise is wonderful. Everyone knows this but how does someone fit it into their life when life won't slow down? This is a tough question to answer but hopefully these tips will help!

Tip #1: Pick an activity you ACTUALLY enjoy!

Exercise is not always something that people get excited about. Yes, we have the go-getters but for a good chunk of the population, it is hard to convince yourself to put your body through activity when it feels too exhausted to do so. This is when doing something you ACTUALLY enjoy can come in to play. For some people, it is a long walk with the dog outdoors to have time to reflect before the day gets started. For others, a group exercise class is the only way they can have fun; as being social and accountable to friends can be a big motivator. Whatever it is, find something that will get you over that tipping point between going or not going when the day has been a long one.

Tip #2: Timing, timing, timing!

A suggestion for caregivers who already have what may be a full day's schedule is to find a time that works for you! For some people that means going early in the morning before their loved one gets up. Others find that taking short exercise breaks (no more than 10 minutes at a time) are a bit more manageable rather than one big chunk. Another popular way of capitalizing on time would be to work out with the person you are caring for. Many newer facilities have multiple classes going on at the same time that can fit a variety of ability levels. Finally, other caregivers set aside exercise appointments for themselves as they believe it is as vital as a medical appointment to make sure they attend. Again, it is important that you find a way of balancing your schedule that works for your life as ultimately this will make or break whether exercise happens.

Tip #3: Don't feel guilty about it!

Exercise is essential. In some parts of the country, physicians are actually giving prescriptions to exercise because they know that the benefits it provides are better than any pharmaceutical drug out there. Exercise for caregivers is not only important for the caregiver themselves, but for everyone else in their life also. It makes you stronger both mentally and physically to deal with what life throws your way. It allows you to continue to be the best caregiver you can be for that person. Exercise, even when done alone, is not selfish. You are taking care of yourself first so that you can be there for those around you.

Take home message: Do something you love doing at a time that works for you and ENJOY it!

Preventing Physical Pain & Injury for Care Partners

Written by: **Brandi La Bonte**



As a person providing care for a loved one (whatever level that may be) you are an integral part of your loved one's healthcare team and the healthcare system in general. Your commitment/actions, though loving and necessary, do not come without both emotional and physical cost. And, while emotional stress and mental health play a role in physical health overall, it is to the physical implications and what you can do to stay healthy that this article speaks to.

A 2014 research study on caregiver risk for chronic pain and injury out of Ohio State University stated that "94% reported experiencing musculoskeletal pain in at least one body part, with the lower back (76%), knees, shoulder and wrist (43% each) being the most common sites for discomfort. More than 78% of caregivers said that the pain impacted their ability to provide care, and 66% said the pain impacted their overall quality of life."¹

Providing care for a loved one can include actions such as assistance with standing up, sitting down or transferring, assisting with care-related tasks like dressing, bathing or even taking on additional household tasks like snow shoveling or laundry. And while these types of tasks are not necessarily difficult, they do require a physicality that includes repetitive movements, bending, twisting, kneeling, etc. The person you are providing care for may also be larger than you and for most, there is no prior experience in proper lifting or transferring techniques. This can lead to not only stress, but physical injury.

It is important to remember when providing care to be aware of your own safety as well as theirs. If you've been on an airplane you've heard the axiom to place the oxygen mask on yourself, BEFORE helping another person. The same adage applies to providing care – you must care for yourself, BEFORE you can care for others. Your health and safety are also a priority!

So What Can You Do to Help Prevent Injury?

A large number of care providing injuries are caused by improper body mechanics when it comes to lifting and/or helping a loved one up. These instances can occur when assisting with day-to-day tasks such as getting out of a chair or the car; or during more serious events like a fall. In fact, according to the Public Health Agency of Canada, falls are the leading cause of injury among older Canadians with 95% of all hip fractures and 40% of all long-term care admissions a direct result of falling.² In Alberta, falls account for 65% of injuries among seniors³ and cost over \$280 million every year in hospital admissions and emergency department visits⁴.

To reduce your risk of back, neck, shoulder, etc. injuries, learning proper techniques and methods to handle physical aspects of providing care is essential. Both Physio- and Occupational Therapists are great resources to help you and your loved one prevent and prepare for situations that have the potential to cause injury. Below are some general guidelines that can help you provide care for your loved one, without hurting them or yourself in the process.

Smart Strategies for Your Health and Safety

- » Be prepared – First, have a conversation with your loved one about the task at hand. What is needed? What role will you each have? Next, ensure the item(s) you need to assist with a specific care task are readily available/close at hand. Then keep communicating throughout the process until the task is complete. Teamwork makes any task easier!
- » Lift smartly - Always keep the person or object you are lifting close to your body and lift with your legs, which are stronger than any other part of your body. Keep your back straight (with its natural curve) and try to avoid twisting motions that take your body out of its natural alignment.
- » Get plenty of rest - Adequate rest is a critical part of managing stress, and for most people, that means around seven to eight hours of sleep a night. When you sleep, your general energy consumption is lowered as, most of the time, your body and brain is at rest. This means more energy can be used to restore your bones and muscles.

- » Drink water - When you're dehydrated, the discs between your vertebrae can shrink and the nerves can become pinched, increasing pain, so drink plenty of water to help keep your muscles and discs hydrated.
- » Exercise - Physical activity can strengthen muscles, reduce feelings of depression and stress, and help you improve your sleep and overall health.
- » Practice or take advantage of relaxation techniques - meditation, yoga, massage and breathing exercises are some of the easiest ways to relieve stress. Research shows that even just one hour a week can result in significant reductions in stress levels.



Helping Someone Up from a Seated Position

1. Make sure that your feet are stable, and as close as possible to your loved one.
2. Face your loved one, slightly bend your knees and squat in preparation to lift. Tighten your abdominal muscles and keep your back straight (try not to curve forward). This will add lifting strength and increase power from your legs & arms.
3. Maintain a position as close to your loved one as possible so that excess strain is not placed on your back by leaning over.
4. Point your feet towards your loved one; and, if possible, place one foot in between their feet and one foot to the outside for optimal stability.
5. Attempt to lift using a smooth, flowing motion, pushing upward with leg muscles; keeping your shoulders and neck muscles as relaxed as possible.

Helping Someone Up After a Fall

1. It is important to stay calm and help your loved one to remain calm. Taking slow, deep breaths can help.
2. Check for injuries like bruises, bleeding, swelling, possible sprains and potential broken bones.
3. Ask them if they are experiencing any pain, where it is located and how severe it is.
4. If there is any sign of serious pain or injury (ie: head injury/ broken bone) do not move them. Call 911 and keep your loved one as warm, comfortable and still as possible until help arrives.
5. When it comes to helping your loved one up it is important to keep in mind that your role is to help guide them through the following steps and keep them steady, not lift their weight. Your loved one needs to be capable of doing the physical work required to get up. If they cannot do this, it may be safer to call 911.
6. If there is no sign of injury and your loved one feels they are able to get up, proceed slowly. Stop at any point if they become stuck, experience pain or become too tired to get all the way up.
7. Find two sturdy chairs and place one next to your loved ones' head and the other down by their feet.
8. Help your loved one roll over onto their side and support them in getting onto their hands and knees, position the chair by their head so that it is directly in front of them.
9. Have your loved one place their hands on the seat of the chair to help evenly distribute their weight.
10. Have them lean forward onto the seat as they gradually bring their strongest leg forward, leading with the knee to place their foot flat on the floor.
11. Move the second chair directly behind your loved one, then ask them to use both their arms and legs to push themselves up and sit back into the chair behind them. Use your hands to keep your loved one steady but keep your back upright and make sure they are doing the physical work to lift themselves.
12. Have your loved one stay seated until you and they are confident that they can stand and continue moving around without hurting themselves or falling again. There is no rush when it comes to safety!
13. Finally, it is important to notify their doctor that they've had a fall and keep an eye out for emerging pain and signs of injury.

References

- 1 Ohio State University Center for Clinical and Translational Science. "Millions of informal caregivers at risk for chronic pain, injury trying to help disabled family members." ScienceDaily, 8 July 2014. www.sciencedaily.com/releases/2014/07/140708091119.htm
- 2 Public Health Agency of Canada. Seniors' Falls In Canada: Second Report. Ottawa: Public Health Agency of Canada; 2014
- 3 Injury Prevention Centre, Edmonton [Database]. Accessed November 2017. Unpublished data available upon request.
- 4 2016/2017 Alberta Health, Analytics and Performance Reporting Branch. Data received August 2018. Costs are based on RIW.

Letting it Go

Dealing with Guilt

Written by: *Brandi La Bonte*

Whether you are a new or long time care partner (be it by choice or chance) it is common for negative-feeling emotions to arise when you are responsible for providing or helping to provide care. Some of these feelings happen right away while others don't surface until you have been doing it for a while. These feelings can include (but certainly are not limited to) anger, irritability, lack of appreciation, resentment, disgust, sadness, embarrassment, loss, frustration, jealousy, impatience and even fear. And as if feeling any or all of those emotions weren't bad enough, then along comes the kicker – the cherry on the negative emotion parfait...GUILT!!

"Oh my god I'm a horrible wife/husband/son/daughter for having those feelings."

"I lost my patience, I'm a terrible human being."

"I blamed him/her for their illness/challenges, what is wrong with me?"

"I can't do this without help, I'm such a failure."

I'm sure there are a few you could add to the list. The bottom line is guilt is an occupational hazard for many care partners. Like smoke in a burning building, the tendrils of guilt can seep into virtually every aspect of providing care – to your loved one and yourself. The guilt can come from so much more than just having certain feelings or reactions; it can also come from our own actions or how OTHERS perceive our actions (or inaction as can often be the case).

You feel guilty for doing too much, guilty for not doing enough. Guilty for not taking time for yourself, guilty for spending any time on your own. Guilty for not visiting your loved one "enough", guilty for ignoring other aspects of your life so you can visit all the time. It can feel like a lose-lose situation.

All these guilty feelings can wreak havoc on you physically and mentally. These "symptoms" of care partner guilt compiled by Home Care Assistance¹ can include:

- » **Basic burnout.** You feel you can't go on. Care partner burnout leaves you fed up and at the end of your rope.
- » **Physical and mental exhaustion.** You are fatigued, weary, not thinking clearly and simply not at the top of your game.
- » **Insomnia and over indulgence.** You can't sleep, you're eating or drinking too much or taking pharmaceuticals to escape reality.
- » **Other parts of your life are falling apart.** You aren't paying attention to your job, family or other responsibilities. You don't have energy or interest for anything.
- » **Frustration.** You are constantly frustrated and nothing seems to ever go right.
- » **Anger and stress.** You're lashing out and snapping more. Care partner stress can leave you angry about life in general.
- » **Depression and lethargy.** You can't motivate yourself to get out of bed or get dressed or go anywhere.

So just what is guilt and/or feeling guilty all about? For many of us, since we were quite small, being guilty is defined as having done something "wrong." And there it is. As care partners it can often feel like you have done something wrong, or at least not done something right. And while there may be small elements of truth to it (maybe you did lose your patience), overall you haven't done anything wrong. To be clear, this isn't meant to excuse abuse of any kind, as that is an entirely different matter.

So what can be done to avoid feeling guilty? The reality is, probably not much. However, while it is improbable to avoid or prevent feelings of guilt, there are certain steps you can take to process those feelings and manage them when they do appear.

First and foremost, acknowledge your feelings of guilt. Ignoring those feelings won't work, unresolved guilt can be like having a snooze alarm in your head! You keep hitting that snooze button, which buys momentary peace, but before you know it the alarm is going off again.

Now it's time to examine the "what?" What led to the actions that now have you feeling guilty? Was your loved one being 'difficult'? Resisting your attempts to help? Were you feeling tired? Pulled in too many directions? Was it all the above? Looking at the "what" can provide context for the situation which, in turn, can help you move forward in a more healthy, compassionate (including self-compassion) and productive way. It is important to note the context here which is quite different from an "excuse" for repetitious poor behavior.

Finally, ask yourself why you are experiencing guilt. The answer will often align with one of the following (or a combination of both):



Unreasonable expectations of yourself.

This is something only you or maybe close family members or friends can help you determine. Try asking yourself these questions though. Are the expectations mine or am I trying to live up to someone else's notion? Am I comparing myself to someone else? Am I judging myself by reasonable standards? Am I frequently putting my loved one's needs ahead of my own?



Being over-responsible for your loved one's feelings or reactions.

You CAN support and care for someone AND be sensitive to their experience with Parkinson's (or any other illness/injury). However, you do NOT have the power to control or change their feelings about their experiences or reactions to those experiences. This is not a reasonable or realistic expectation for any care partner; or any one for that matter.

It is important to remember that just because you feel guilty doesn't mean it is warranted. If it is warranted, take your share of the responsibility, learn from it, move forward and forgive yourself. If it isn't warranted, let the guilt go.

References

- 1 Popp, Cheryl. Home Care Assistance. How to Let Go of Caregiver Guilt. Homecareassistance.com

Safely Working Towards In-Person Support Groups

Written by: **Brandi La Bonte**

As we move forward through COVID and into the fall/winter seasons Parkinson Association of Alberta will be determining whether or not a Support Group will take place in-person or via ZOOM/call-in on a case by case basis. Determining factors include current COVID outbreaks, client registration for the Group, AHS/Alberta Government guidelines, and/or weather.

The challenges with COVID & weather mean the ability to adjust quickly is important to keeping our Support Groups running smoothly. To ensure that we can pivot when necessary AND keep you informed quickly, we implemented registration for each and every Support Group you attend.

This will ensure that:

- » Participants are aware of WHERE (*in-person or ZOOM/call-in*) the Group will take place
- » We have the ability to contact registrants to let them know if a location changes
- » We do not exceed maximum capacity (*we have spacing and capacity restrictions at many locations*)
- » We have enough participants registered to run a Group

The **required registration** will also help us in the event that COVID contact tracing needs to occur. For more information and to register, please contact your Regional Client Services Coordinator or call us toll-free at **1-800-561-1911**.

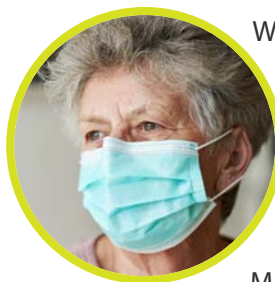
It is our sincere hope and desire to get back to AND be able to continue to run Support Groups in-person (so long as it is safe to do so). To accomplish this, we are going to need YOUR help!

When it comes to in-person Support Groups you are going to notice some changes (in addition to required registration):

- » Chairs will be spaced 6 feet apart
- » We will not be serving (or encourage sharing of) communal coffee/snacks – you will need to bring your own – for you and your loved one ONLY
- » Your Support Group may be in a new location
- » Your Support Group may be divided into smaller groups within the room to ensure everyone can hear and communicate with each other
- » You will be asked basic COVID-safety questions every Support Group
- » You will be strongly encouraged to wear a face covering/mask (I know this is a hot topic so please read on)

Wearing a mask has become a bit of a contentious issue these days and finding a way forward in regard to this issue has led to a lot of research and healthy debate – amongst our staff and our clients. What we've come up with is that there is no, one right answer. Maybe wearing a mask is mandatory in your community and maybe it isn't. Maybe you think masks provide some protection or maybe you don't. It is OK to feel how you feel on the subject. I would however ask you to consider this...

Your Client Services Coordinators serve over 2800 individuals and families across Alberta. They travel to many communities across their Regions, and come into contact (either via Support Groups or one-on-one support) with people who are both quite healthy/low risk and medically vulnerable/high risk. They follow all the necessary protocols to keep not only YOU and the rest of the Parkinson's community across the province safe, but themselves and their families as well. As much as they are able (and when appropriate) they maintain social distance, wear a mask and frequently hand wash/sanitize.



With your help we can keep this incredible, caring and committed team safe, so they can continue to keep you and the rest of the Parkinson's community healthy and safe! So, what does this mean for you?

We are strongly recommending that you wear a mask at in-person Support Groups.

Many communities have mandatory mask policies, so it is a given, but some communities do not. For those that do not, we are humbly asking if you would consider wearing a mask for your Support Group. If not the entire time, at least until you are seated. Of course, if you have any medical concerns when it comes to mask wearing (including anxiety) please just let your Coordinator know when you register!

If you have any questions or concerns, please do not hesitate to contact your Regional Client Services Coordinator or give me a call 780-425-6400 or toll-free at **1-800-561-1911**.

SUPPORT GROUPS

ALBERTA (ZOOM/CALL-IN ONLY)	1-800-561-1911
1st Tuesday – DBS/Duodopa	1:00PM
1st Thursday – Widows/Widowers	9:30AM
2nd Wednesday – Under 55	7:00PM
3rd Thursday – General Parkinson's	10:00AM
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
2nd Tuesday – Southeast	10:00AM
3rd Tuesday – Care Partners	1:30PM
3rd Thursday – Southwest	10:00AM
4th Tuesday – Southeast	10:00AM
4th Tuesday – Young Onset	7:00PM
CANMORE	
2nd Thursday	1:30PM
COCHRANE	
2nd Thursday	10:00AM
NANTON/HIGH RIVER	
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
SHERWOOD PARK	
2nd Tuesday	1:00PM

EDMONTON REGION...continued	780-425-6400
ST ALBERT	
3rd Tuesday	10:00AM
WESTLOCK	
Last Monday (Nov, Jan, Apr)	1:30PM
WHITECOURT	
3rd Thursday (Nov, Jan, Apr)	1:00PM
GRANDE PRAIRIE REGION	780-882-6640
GRANDE PRAIRIE	
2nd Wednesday	2:00PM
4th Wednesday – Care Partners	11:00AM
LETHBRIDGE REGION	403-317-7710
LETHBRIDGE	
3rd Thursday	2:00PM
LLOYDMINSTER REGION	780-808-5006
BONNYVILLE	
3rd Tuesday	10:30AM
LLOYDMINSTER	
2nd Monday - Care Partners	10:00AM
4th Tuesday	2:00PM
VERMILION	
2nd Tuesday	1:00PM
MEDICINE HAT REGION	403-526-5521
MEDICINE HAT	
4th Thursday	1:30PM
RED DEER REGION	403-346-4463
CARE PARTNER (ZOOM/CALL-IN ONLY)	
3rd Thursday	2:00PM
CASTOR	
4th Tuesday (Feb, Apr, Jun, Aug & Oct)	1:30PM
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	
1st Wednesday (Feb, May, Aug & Nov)	1:30PM

REMINDER: Advance REGISTRATION is required for each and every Support Group.

Please note that Support Groups falling on November 11 have either been cancelled or rescheduled and that December dates may vary!



Dear Friends,

Greetings from the team at Parkinson Association of Alberta (PAA). I am reaching out to thank you sincerely for your ongoing support and your relationship with PAA as a member, donor, partner or volunteer. Because of people like you, we were both prepared for and have been successful staying connected with our Parkinson community. We are pleased to report that our Client Services Team has personally made phone contact with over 2,000 clients, run 160 support groups and delivered nearly 470 hours of unique online supportive, educational, motivational and physical programming since March 16th, when Alberta followed the world example of isolating.

The COVID-19 pandemic restrictions have hit people in a variety of ways with unique and sometimes devastating outcomes. We are committed to remaining a source of comfort and support as we continue to navigate confusing and stressful waters.

Prior to our change in circumstances, PAA was working with partners at Brain Canada and Parkinson Canada to bring you an educational event (Hope Conference) this fall. We can announce that we are still able to do that virtually and we invite you to save the date. Saturday, November 28th, you will be able to participate in this opportunity to learn and connect with leaders from across the country. All free of charge, thanks to our friends at Brain Canada. The details of the agenda are not quite finalized but we will keep you informed on both our website and via email.

This letter is also a reminder to renew your membership (or purchase one). Your commitment to just \$25 a year through memberships ensures your voice is heard for the future of our organization. You join a community of support and understanding where common experiences create lasting bonds and connections. You add to our ability to demonstrate value in the work we are so honoured to do.

December is also a time of year where we are thinking about our annual donations and the upcoming tax season. Canada has a generous tax credit system for donors to charities and the benefits can be significant. Our members make up the number one single source of operational revenue and we couldn't do what we do without your generosity.

A note from Keith and Carol Williams (PAA Members)

Nearly a year ago we got the diagnosis that my wife Carol has Parkinson's disease.

This was really disheartening as we had lost my older brother Don just two years earlier after a long stretch of years fighting this dreaded disease. He, along with a friend of ours for more than 50 years, were both showing the signs of a losing battle, and it left us with a sense of dread.

During Don's years of illness, he was a regular at the support group in our area. Not easily suppressed, he was very supportive of the others in the group, and the experience was regarded as a lifeline for both Don and his wife.

We are finding the support group, including many of the same members who knew Don, to be very welcoming and open about their experiences, fears, hopes, tricks tried, and how they try to cope. After the first meeting, Carol was with the "Parkies" and I went with the caregivers.

Both of us thought that the experience was a little scary, but really helpful. The personal stories, questions, and advice shared at the meetings has made the meetings something we look forward to.

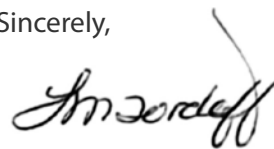
The follow-up emails and phone calls from Emma, our coordinator, really make the contact seem personal. We will survive this process and our hope is that those we share our story with will also benefit now and in the future.

Your membership and donations ensure we continue to offer help today and hope for tomorrow for people like Keith and Carol. We will embrace 2021 much the same way we did 2020. We are hoping for a COVID-free environment but will adapt as need be to ensure we continue in our quest to be available and an important resource to all people living with Parkinson's in Alberta. Our team is here for you. Please contact me directly with any questions or comments.

Don't forget to visit our website for a wealth of information and both provincial and region-specific programming.

Thank you for your membership and for continuing to be part of our PAA family.

Sincerely,



Lana Tordoff,
Chief Executive Officer
Parkinson Association of Alberta



Please fill out and mail to PAA Calgary Head Office
120, 6835 Railway St SE, Calgary AB
T2H 2V6

Personal Information

Mr. Mrs. Miss Dr.

First Name: _____ Last Name: _____

Address: _____

City: _____ Prov: _____ Postal: _____

Phone: _____ Email: _____

- Person Living with PD Spouse/Partner has PD Family Member/Friend Professional Health Provider
- I would like to learn more about volunteering
- I would like to receive email communications from Parkinson Association of Alberta (including newsletter, updates & information)

Membership

Membership is \$25 annually and runs from January 1 to December 31.

- I wish to BECOME a member I wish to RENEW my Membership
- I would like my Parkinson Pulse Magazine mailed to me

Donation

Donations of \$20 and up will be receipted.

I wish to make a DONATION in the amount of: \$ _____

In Memory of _____ In Honor of _____

Please send a notification of this gift to (name and address): _____

Payment

Enclosed please find my cheque (made payable to Parkinson Association of Alberta) or cash for \$ _____

Please bill my: Visa Mastercard American Express

Name on Card: _____

Card Number: _____ Expiry: _____ CVD: _____



is a Wrap!

Written by: Alicia Jeffrey

On behalf of the staff of Parkinson Association of Alberta and Board of Directors, we thank you for your generous support for this year's 8th Annual Flexxaire Parkinson Step 'n Stride. Despite our new normal, we successfully hosted our first virtual event!

We can celebrate that, with the passion and commitment of our sponsors and participants, their families and countless supporters, we have reached nearly \$260,000 and counting! We can also celebrate that the average dollar amount raised by individual's was \$495, we had over 700 mentions on the radio, and social media, and from the funds raised we will be investing 96% directly back into our Parkinson's community.



We are committed to ensuring we have the resources, information and programming available to provide help today and hope for the future for people living with Parkinson's. Thank you again for your commitment to our largest fundraising of the year and we hope are looking forward to 2021 Step 'n Stride on September 11th and 12th.





FLEXXAIRE



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JAGUAR

JAGUAR ROYAL OAK



VALENTINE VOLVO



CHARTWELL
retirement residences



Thank You



FLEXXAIRE



Step 'n
Stride

Happy Holidays!

As the holiday season approaches, there is no greater joy than the opportunity to express to you and your family our warmest wishes and season's greetings.

We hope your holidays will be filled with joy and laughter, health and happiness through the New Year.

*From the board and staff
Parkinson Association of Alberta*

