

Parkinson PULSE

Connecting people living with Parkinson disease in Alberta



PARKINSON DISEASE

IT'S A *Family* AFFAIR



Cover Story P.6

Parkinson Disease...It's a Family Affair

Talking to Kids

Talking to Children about
Parkinson Disease

P.8



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Summer 2016

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Parkinson Alberta

Parkinson 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.

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Please visit our website:
www.parkinsonalberta.ca/aboutus
to view our staff and board list.

Parkinson Pulse is available (both past and present issues) as a free download via our website.

We welcome your comments, suggestions and questions. Email us at communications@parkinsonalberta.ca; or call us toll-free at **1-800-561-1911**.

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Contact:
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From the Desk of **THE CEO**

Having Parkinson disease can change the dynamics of family relationships. Processing the news of a Parkinson diagnosis can bring a flood of emotions and questions to the person receiving the diagnosis, as well as their loved ones. And, in addition to dealing with the Parkinson's itself, other issues will need to be addressed including lifestyle, finances, the ability to work, intimacy, and emotional and practical support for everyday life. The good news is you do not have to face a Parkinson's diagnosis alone.

Letting people you know that Parkinson's has affected you (or your loved one) is not always an easy task, but it can be especially daunting for those with children or grandchildren. In this issue ([page 8](#)) we address this unique challenge. Regardless of who you would like to share news of a diagnosis with, if you find you are having trouble finding the right words or are unsure what to say, you may want to connect with peers at a support group or talk to a Client Services Coordinator who can help.

After people with Parkinson disease, spouses/partners are the clients we work with most. For those couples who live and deal with Parkinson's and everything that comes with it on a daily basis, life can oftentimes feel like a rollercoaster with ups and downs, twists and turns. With the blessing of his wife, one of our own has shared his story on [page 12](#) in a piece he titled "Parkinson's, Marriage and Caregiving". It is an honest and genuine glimpse into one man's perspective on life with Parkinson's. And he is not alone, we hear from people across the province with similar stories, triumphs and frustrations. Like him, YOU are not alone.

Parkinson Alberta can help you and your family build a strong network of support and services that you can rely on. We also provide the tools to help you effectively communicate and manage the day-to-day aspects of Parkinson disease. From support groups to programs and education, to the one-on-one, home visits and telephone support we offer – we want to make sure everyone has the means to live well and /or help others live well with Parkinson disease.

People often ask my staff and I; "How can we, as a family, make a difference in Parkinson's?" The answer is simple, find a way to get involved. When you get involved in the Parkinson Community everyone benefits...you, your family and loved ones, the medical community, your city/

town/region, and other Albertans affected by Parkinson disease.

Getting involved means different things to different people. There are six key types of involvement—volunteering, donating, sharing stories/experiences, educating, decision making, and of course, fundraising.

Volunteering is a great way people of all ages can get involved. Whether it's at an event (Step 'n Stride, poinsettia campaign, casinos, etc), project-based (Brighter Day Program) or day-to-day (office help, phone calls) volunteers help make a real, tangible difference! Donating to Parkinson Alberta is as easy as clicking a button with our online system. Sharing your story (in our magazine or on our website) and/or your knowledge with others not familiar with Parkinson disease is a great way to help raise awareness. Joining one of our many committees or our Board of Directors will help determine the path as we continue to move forward.

Last, but certainly not least, is fundraising. We host many small and large fundraising events throughout the year. With no consistent funding sources (including government), fundraising is one of our main sources of revenue ([page 16](#)). Our largest fundraising event of the year is our annual Step 'n Stride Walk.

With Step 'n Stride only a few weeks away, we encourage you to come together as a family, create a team, raise funds and have fun all in the name of Parkinson's! Our Flexaire Parkinson Step 'n Stride is one of our greatest family events and is the epitome of what Parkinson Alberta is all about...coming together as a community, as a family to help the people we care about live the best lives possible with Parkinson disease. As an organization it also means reaching out across the province to ensure that no one person and no family has to face a Parkinson's journey alone. We ARE here to help, every step of the way with support, education, resources, programs and funding for research. Help us, help them...See you at Step 'n Stride!

John Petryshen
CEO, Parkinson Alberta



WE NAVIGATED THE JOURNEY TOGETHER

By: Laurel-Anne Millis

Choosing to lovingly care for him was like steering a plane into a mountain as gently as possible. The crash is imminent; it's how you spend your time on the way down that counts.

(Hotel on the Corner of Bitter and Sweet by Jamie Ford)

My husband Neal was diagnosed with Multiple Systems Atrophy (MSA), an aggressive and rapidly debilitating form of Parkinson disease in June of 2012. He died in August 2015. The best advice I received was "don't get too far ahead of yourself" (my massage therapist). Looking back I think what helped us cope best was learning to accept assistance (also advice from my massage therapist). It was one of the toughest things we had to learn.

During the period following and for approximately two years prior to diagnosis, Neal and I navigated the often chaotic journey together with the help of family members, friends and professionals. Then we chose to take advantage of AHS's Self-Managed Care Program. We were fortunate to hire amazing, loving, accommodating care givers, one of whom lived with us for 2 ½ years and became like family. Having consistent, reliable caregivers was paramount in living a quality existence.

We learned to accept the many, many gifts of friendship: a meal, night coverage so I could get a solid night of restorative sleep, strong arms to assist with going on an outing or a calm ally in evaluating medical decisions. Choosing to use Home Care, including Palliative Care gave both of us a quality of life that we could not have hoped for if we had insisted on independence. We chose to engage in as much as Neal was capable of, including: Brighter Day Program (MRU and Parkinson Alberta), being a subject for neurologist learning at the University of Calgary; watching Calgary Stampeders in our living room with our long time season ticket holder friends when Neal could no



longer climb the stairs or stand the heat; time spent each morning having breakfast together and reading the newspaper and many trips to Dairy Queen.

In reference to her own husband's illness and death, someone had told me "...I don't think there was anything more I could have done..." That became my goal. In hindsight, I feel good about what I chose to do...although I would still love to hold his hand one more time.

If you would like to share your story, please email communications@parkinsonalberta.ca or talk to your regional Client Services Coordinator.



Ask the EXPERTS +A

Parkinson Alberta has gathered an exemplary team of experts to answer your PD questions in a feature on our website aptly named "Ask the Experts". Our experts address questions on everything from symptoms and treatments, to medications and research, to alternative therapies.

Question: My dad is 84 and has been diagnosed with Parkinsonism. He is on Levocarb and we reduced the dose recently with no major effect on his physical conditions. The problem that is bothering him the most lately is hallucinations. His "pixies" keep him up at night with all the "construction they do in his residence." He used to understand they were not real but now he says he has talked to them and they really do exist. Should I continue to explain they are not real? Should we try to get him on some anti-hallucination drugs?

Answer: As the symptoms of Parkinson's advance, a common problem is the development of visual hallucinations. At the beginning, the person with Parkinson's has insight into the fact that they are not real, but then this insight may be lost as is happening with your father. The first step in treatment is making sure there are no other medical problems, such as urinary tract infection. If everything checks out okay, the next step is review of the PD medications. Some medications such as amantadine and dopamine agonists can exacerbate hallucinations, and may need to be discontinued.

Secondly, the total dose of levodopa may need to be decreased. If the hallucinations persist, there are several medications, such as quetiapine that can be used to decrease them.

Finally, the person would need to be evaluated to see if they are developing cognitive problems, which could be contributing to the hallucinations. This can be treated as well. We encourage you to speak with your dad's neurologist to determine what tests need to be done, and the best treatment option.

Question: My mother was diagnosed with Parkinson's about 15 years ago and she was able to manage her condition fairly well. About 1.5 years ago she fell and broke her hip, and had to have a hip replacement. Since then she has gone downhill and one of her main complaints is the lack of oxygen close to her dose of dopamine. She is terribly uncomfortable and we are wondering if this problem with breathing is because of her Parkinson's or if it is related to anxiety but we don't seem to find comfort for her. She is getting very depressed. Is there something we can do for her? She has had lung tests, she has oxygen available but nothing seems to help. Thank you!

Answer: When the dopamine level in the brain decreases in a person with PD who is taking levodopa, the symptoms are referred to as "wearing off". The motor symptoms of "wearing off" include tremor, slowness and stiffness. Over the past decade, neurologists have become increasingly aware that there are many non-motor symptoms of "wearing off", including depression, anxiety, bloating, and fatigue. One of the main types of non-motor "wearing off" can be a feeling of shortness of breath. Your description that your mother's symptoms of shortness of breath come on just before the next dose of medication is due, is very suggestive of this (and other tests have been normal). The main treatment is adjusting the medications to prevent the "wearing off". Please speak to the physician looking after your mother's PD about how the medications could be best adjusted.



Don't live alone with Parkinson disease.

We can help.

All you have to do is start the conversation.

PD HELPLINE

Call 1-877-243-9992

Monday to Friday

8:30 am till 4:30 pm

Free from anywhere in Alberta

PARKINSON DISEASE... IT'S A FAMILY AFFAIR



Parkinson disease affects the lives of everyone it touches. From the person who received the diagnosis, to spouses/partners, children, and other family members to your larger circle of influence – friends, neighbors, co-workers and community. Life as you know it changes the moment a Parkinson's diagnosis is received. For some there is the instant relief of being able to put a name to your symptoms, for others there is denial, anger, fear and yes even grief. For all there will be a new journey in store; as the diagnosis of Parkinson disease creates a need for a “new normal”. Not only will daily patterns change, but also expectations of how you will live, love, and lead the best life possible. The decision to “face” Parkinson disease as a family (and extended circle) can mean that the proverbial “weight of the world” is lifted and shared; and the bonds of family can be strengthened.

Knowledge is Power

The first step for everyone is understanding Parkinson disease and accessing the best and most accurate information possible. Many people turn to the internet for information and answers; this can be both a blessing and a curse as not every website offers legitimate, medical-fact based information. It is important to be able to distinguish between factual information and advertisements. Parkinson Alberta offers not only knowledgeable staff and a website chock-full of helpful information and content; but a large array of printed resources at our disposal.

Reading, observing and asking questions is how many of us learn. If you are a person with Parkinson disease be sure to keep a list of questions as you think of them for

doctors and other health and support professionals. For a spouse/partner it is important to ask your questions as well...not only of the medical and support professionals, but of your loved one. For other family members, it may vary – especially in the case of adult children. On one hand, many parents do not want to “burden” their adult children and as such may not give a complete picture of their day-to-day struggles with Parkinson's. On the other hand, offering unfettered advice without fully understanding Parkinson disease and/or their current reality, may lead to hurt and hard feelings. Be sure to ask questions and observe to ensure that your parent(s) are not becoming overwhelmed. Knowledge is definitely power, but communication is everything!

Telling Others

Making the decision to let others know about a Parkinson's diagnosis is a very personal decision; and one that can cause stress and anxiety. Do I tell my spouse/partner? My kids? My siblings? My yoga group? My boss and co-workers? My hairdresser? Do I have to tell everybody? Do I have to tell anybody?

Ultimately there is no one right decision, the choice of who to tell and when to tell is yours. “Going it alone” is certainly an option, but one that can add undue stress which can in turn worsen Parkinson's symptoms as well as one's mental, emotional and physical well-being. If you do decide to include others a good place to start is with those who are closest to you. As Parkinson's is a progressive disease, over time symptoms will become more pronounced; it may be at those times you may want to include others. By choosing to include others in a Parkinson's journey, you can ultimately increase your circle of support and understanding.

Lean on Me

Many will want to help, but will be unsure of how to best accomplish that. For those wanting to help a person with Parkinson disease or their spouse/care partner the best thing to do is ask! Similarly, people with Parkinson's and/or their spouse/care partner need to learn not only to let people know what help is needed, but to accept those offers. Leaning on each other for support, be it emotional or physical, is how we ensure we are all leading the best lives possible!

Parkinson disease can rewrite relationships in negative and positive ways; and families who face both as a family unit/team often find that they build stronger family bonds and build memories that will last a lifetime.

NEWS + updates

- » Take a Swing at Parkinson's with our PD & Boxing programs! Our first program was piloted in Sherwood Park this past Spring. With positive feedback in abundance we are excited to expand the program. Edmonton's program began in August, Calgary's will follow this September and Red Deer's this Fall! For more information on our current or upcoming programs or if you are interested in the possibility of this program starting in your community, please contact your **PA Regional Office (contacts on page 2)** or **call toll-free 1-800-561-1911**.
- » Are you interested in learning about Parkinson disease from those who live and deal with it on a day-to-day basis? Join us in Medicine Hat on **Thursday, September 19** at 6:30PM as Parkinson Alberta presents a panel discussion on Parkinson disease in partnership with the Medicine Hat Public Library. For more information please contact **PA Medicine Hat Office at 403-526-5521**.
- » Tell Your Story... As one of our Storytellers, you aim to show the personal side of Parkinson disease by sharing your own unique experience. We are looking for your story, your experiences, your struggles and inspiration.

Storytellers can write or record (audio or video) their stories; and stories will be shared in the Faces of Parkinson's section of our website; written stories may also appear in our quarterly magazine. Please note that stories don't have to be "stories" they can be poems, songs, or photo collages.

For more information on how to submit your story talk to your Client Services Coordinator or visit our website at www.parkinsonalberta.ca/facesofparkinsons-tellmystory.



Rally Your Team

Rally your #ParkinsonPosse, suit up and join us at the annual Flexxaire Parkinson Step 'n Stride this September 10 & 11, across Alberta.

The best way to ramp up the fun, crank up the excitement, and generate pledges is to unite your team. Teams come in all shapes and sizes and can be made up of your family, friends or coworkers. Show your kids and grandkids what a community looks like by letting them in on the action too!

Pick a theme and let the crowd know who and what you're walking for. Come out as cowboys, clowns or just plain colourful. However you do it, whomever you do it with, show off your team by sharing your photo on Facebook and Twitter and tagging us at **#ParkinsonPosse**.

Register Today!
parkinsonalberta.ca/stepnstride

THE KID CONNECTION...TALKING TO CHILDREN (AND TEENS) ABOUT PARKINSON DISEASE

When it comes to children, talking about Parkinson disease is a very personal matter. When do you say something? What and how much do you say? How much should I involve them?

For some children, a parent, grandparent, other family member or close friend has always had Parkinson disease; they've never known the person without Parkinson's. For many however, that is not the case. Either way, at some point families must deal with the unique challenges that come with talking to kids about Parkinson disease.



When do you say something?

After receiving a Parkinson diagnosis you may feel relieved to finally have a name for your symptoms; for others it may take some time to gather one's bearings and begin moving forward. Talking to the children in your life may seem like the farthest thing from your mind. For some it's a protective instinct or a worry of burdening a young one. It is important to note however, that children often instinctively know when something is not quite right—be it physical or emotional. With Parkinson disease comes physical changes as well as emotional fluctuations (stress, tiredness, apathy, etc); as such keeping a diagnosis secret from children (who are often very perceptive) may not only be futile, but cause them unwarranted anxiety.

What and how much do you say?

- With adults it is often easier to have a conversation about Parkinson disease. With children, especially younger ones, it can be difficult to find the age appropriate words to explain Parkinson's. Children's age, maturity levels and relationship to the diagnosed person are all factors that may be taken into consideration, along with personal preference.
- The first step in talking to kids, regardless of age, is to be prepared and be open (especially with teens and older kids). How much you should say depends on the age and maturity level of the child or children you will be speaking to. For a younger child simply explaining Parkinson's in a manner such as "A part of Daddy's brain isn't working quite right and it makes him move a little bit slower" might suffice. An older child or teenager however will most likely need more specific information.
- Finding age-appropriate language is also important. While older children may be fine with most of the Parkinson's terminology; for younger children, explaining symptoms in simple terms can make it easier for them to understand what is going on. For example saying "See how Grandpa's hand shakes?" may be easier to comprehend than "Grandpa has a tremor." Or, "When Mom 'freezes' it's a little bit like when you hit pause on your movie."
- Ensure that children know that it is okay to ask questions. Some of the most frequently asked questions include: "Are you going to die?" "What is Parkinson disease?" "Will I get it?" and "Is it my fault?" Many families opt to hold a "family meeting" to let their children/grandchildren know about a diagnosis. Others have done a one-on-one style. Not every child is a talker or "sharer", so it may be harder to tell if there are questions they would like to ask or fears that need to be alleviated. A good suggestion for this is to have literature (brochures or books) handy in your home and reliable websites bookmarked so that children can view them when they are ready. Some even invite children to attend support groups, programs or education sessions with them.



How much should I involve them?

Don't be afraid to let children see your Parkinson's... especially when you are off. Parkinson disease is not always easy to understand (even for adults), so letting children see the difference between being "on" and "off" can help put things into perspective. It can also help them understand why sometimes you can do things "normally" and other times you need to have a break. Younger children are often keen to help! Getting Papa his cane, bringing the spoons to help Uncle set the table or helping Mom water the plants is a way for them to feel helpful and appreciated. For older children helping out is a great way to teach self-sufficiency and empathy – whether it is helping Grandma bake a favorite cookie, Dad mow the lawn or filling the car with gas for Auntie. Learning new skills helps increase confidence.

Bring them along to volunteer at a Parkinson's event or encourage them (and the whole family) to be on "your team" for the 2016 Flexaire Parkinson Step 'n Stride (see more on page 10 and 19). This event is really all about family and the Parkinson Community! We make it family friendly especially for your tiny and not-so-tiny team mates. Give children a pledge sheet of their own or charge them with coming up with a team name or theme. Not only is instilling the value of helping others priceless; but as a parent, grandparent, or other family member you always cheer for them. Give them the opportunity to cheer for you!

A couple of things to remember

Being diagnosed with Parkinson disease does NOT make you any less of an authority figure (be it parental or otherwise). It is imperative for children to understand from that aspect there has been no change. The stability of boundaries, influence and yes, even discipline remain in full affect.

Having Parkinson's does however mean that there will be times (or a point) when things either cannot happen, or cannot happen in the same way; as such it is important to manage expectations to avoid disappointment. Balancing optimism with reality is crucial.

Conversations and discussions will be ongoing, change over time and over the course of the disease. Establishing a good, open and honest line of communication with children early on in a diagnosis can not only help ease anxiety as the disease progresses; but help your family move forward in a positive and supportive way.

If you need help talking to the children in your life, our Client Services Coordinators are available to help!

RESOURCES TO HELP TALK TO KIDS ABOUT PARKINSON'S

- The Parkinson's UK website has a series of four (My Dad/Mum/Gran/Grandad Has Parkinson's), children's books for ages 3-7 available to order or free for download.

www.parkinsons.org.uk/content/talking-children-and-teenagers-about-parkinsons

- I'll Hold Your Hand So You Won't Fall – Rasheda Ali
- Who is Pee Dee? – Kay Mixson Jenkins

FOR TEENS AND OLDER CHILDREN

- Parkinson's in Your Life: A Guide for Teenagers www.parkinsons.org.uk/content/talking-children-and-teenagers-about-parkinsons

The Countdown to STEP 'N STRIDE IS ON...



September 10 & 11, 2016

#WhyIWalk



The 2016 Flexxaire Parkinson Step 'n Stride is our largest annual fundraising effort to provide the support, programs, education and essential funds for research that make every day better for those with Parkinson disease and the people who care for them.

Over the course of two days, September 10 and 11, Parkinson Alberta will host TEN walk events throughout Alberta; including our newest location... Bonnyville!! We invite you to join us this Walk Weekend as we celebrate movement, health and wellness in the Parkinson's Community.

Each event will include either lunch and/or snacks, special guests, entertainment, and of course, the best part of the day -- the camaraderie that goes along with gathering together with your family, friends and teams to participate in the Walk itself!

****NEW**** this year will be a spotlight on health and wellness options and opportunities available in your community for both you and your loved ones! Take in demonstrations and/or vendors from the health and wellness community. Want to be a part of our health and wellness spotlight? Contact your Regional Office today.

Want to avoid the line ups on Walk Day? Many of our Regions will be hosting pre-registration events to keep your wait time down. Be sure to check our website (www.parkinsonalberta.ca/stepnstride) or call your Regional Office to see if a pre-registration event is being held in your Region.

Register Now

PARKINSONALBERTA.CA/STEPNSTRIDE

Finally, this past June we ran our first Flexxaire Parkinson Step 'n Stride media campaign. Thank you to everyone who called, emailed or let us know that they heard or saw our ads! Our second campaign is set to run August 29 through September 9.

- » Our TV campaign will run on Edmonton and Calgary's CTV stations
- » Our radio campaigns will run on the following stations
 - » 840 CFCW (Edmonton, Lloydminster, Red Deer and some areas in the Calgary Region)
 - » Cool 103.3 (Bonnyville)
 - » 98.1 CAM FM (Camrose)
 - » AM 770 Talk News (Calgary/Cochrane)
 - » Country 105 (Calgary/Cochrane)
 - » 96.3 Capital FM (Edmonton)
 - » Big Country 93.1 FM (Grande Prairie)
 - » 95.9 Lloyd FM (Lloydminster)
 - » 102.1 CJCY FM (Medicine Hat)
 - » 95.5 FM KG Country (Red Deer)
 - » At press time, we were still working on our Lethbridge campaign

Be sure to watch our Facebook page for any upcoming media announcements!

EVENTS

+ updates

UPCOMING EVENTS

For more information on our upcoming events, please visit our website at www.parkinsonalberta.ca

Flexaire Parkinson's Step 'n Stride – VOLUNTEERS NEEDED!

This September, TEN locations will hold a Step 'n Stride event! Step 'n Stride is our largest fundraising event of the year; accounting for over 55% of our annual fundraising revenue and helping PA secure funds for support services across the province as well as funds for research! We are currently looking for volunteers to work at all event locations. Contact your Regional Parkinson Alberta Office, call toll-free (1-800-561-1911) for more information or to volunteer.

I Love a Parade!

Our PA Lloydminster Region undertook a parade circuit this past June/July with stops in Wainwright, Bonnyville and Lloydminster! With two separate themes (living well and research), a surprise guest in Canadian Cruiserweight Champion Rob Nichols and even a second place prize; it's been a summer for Parkinson's Awareness!



2016 SAVE THE DATES

September 10 & 11

Flexaire Parkinson Step 'n Stride (province-wide)

October 21

sip sample support – an evening of hope and travel (Medicine Hat)

October 22

sip sample support – a taste of the market (Calgary)

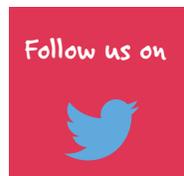
November/December - Parkinson Alberta Grows Poinsettia Campaign

For more information on these and other events in your Region visit www.parkinsonalberta.ca/in-your-region



PAST EVENTS

Our 25th Anniversary Parkinson Tulip Tournament was a resounding success! With new sponsors, golfers and activities, this year's tournament was a day filled with fun, laughter and of course support for Albertans affected by Parkinson disease! A big "THANK YOU" to all of our volunteers, sponsors and donors who have contributed to the success of our golf tournament for 25 years! Without your support and that of our fun-loving golfers, we would not be able to accomplish our mission off the course... and that is to ensure no Albertan has to face Parkinson disease alone. We look forward to seeing everyone again next year!



IT AIN'T EASY BEING GREEN

Parkinson's, Marriage and Caregiving

By: Ian Barnes

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 fulfil 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 Alberta 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 counsellor 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. It ain't easy being green.



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 and 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 and/or 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!

HELP CHANGE THE FUTURE OF PARKINSON DISEASE...

Participate in Research

Researchers around the world, including right here in Alberta, are working to identify and address various issues associated with Parkinson disease. Clinical trials are a key component of research and are at the core of all medical advances. One of the biggest challenges associated with research (besides funding) is a lack of participation. Oftentimes, studies may not even proceed due to a lack of participant enrollment.

People participate in research for a variety of reasons; however, the motivating factor for most is to help others and contribute to moving science forward. If you feel participating in a research study is something you are interested in, we encourage you to view the available opportunities to find out if there is a good match available for you. Please note that interested individuals are not necessarily guaranteed acceptance into a study.

LONGITUDINAL STUDY OF MILD COGNITIVE IMPAIRMENT IN PARKINSON DISEASE

The University of Calgary together with the Hotchkiss Brain Institute are conducting an observational research study to get a better understanding of the development of thinking and memory problems in Parkinson disease (PD) compared to thinking and memory problems in general aging.

Who is eligible to participate in the study?

- » Men and women 60 years of age or older
- » Patients with Parkinson disease with and without mild cognitive impairment
- » Patients without Parkinson disease with and without mild cognitive impairment
- » Healthy volunteers without history of Parkinson's or memory complaints such as spouses/partners (not blood related) of patients with PD

WHAT IS REQUIRED OF THE PARTICIPANTS?

Your participation will involve:

- » Eight (8) in-person visits over the course of the three year (36 month) study
- » At the initial visit, a one-time blood sample will be drawn for DNA collection
- » Your mood, memory and thinking will be assessed; this involves performing a series of tests and answering questionnaires
- » PD symptoms will be assessed
- » You will be asked to undergo five (5) MRI scans of your brain throughout this three year study

DOES OUTPATIENT PALLIATIVE CARE IMPROVE PATIENT-CENTERED OUTCOMES IN PARKINSON DISEASE?

The University of Alberta is conducting a research study to investigate the outcomes of patients with Parkinson disease receiving palliative care versus usual care. The goal of the study is to determine whether palliative care will improve patient quality of life and caregiver distress compared to usual care with a neurologist. Palliative care involves looking at all symptoms of Parkinson disease including: pain, caregiver distress, loss of hope in either the patient or family and using a team to work with you to find solutions. Palliative care approaches can be used AT ANY TIME of an illness to provide patient-centered care.

WHO IS ELIGIBLE TO PARTICIPATE IN THE STUDY?

You are eligible to participate in this study if you meet all of the following criteria:

- » You are a fluent English speaker over the age of 40 years
- » You have a diagnosis of probable Parkinson disease
- » You live in Edmonton, AB or surrounding communities

What is required of the participants?

- » Take part in five (5) clinic visits and four (4) telephone assessments over the course of one (1) year
- » If you are in the palliative care group, you will see the palliative care team in addition to the above clinic visits and telephone assessments
- » Each clinic visit/telephone assessment will involve answering questionnaires

A RURAL PERSPECTIVE OF LIVING WITH PARKINSON DISEASE

Researchers at the University of Calgary want to understand what it is like living with Parkinson disease in rural communities and what you do that helps you live with Parkinson disease. The information you and your partner share with us may help improve health programs for people with Parkinson's. It may also help health care professionals give you better care.

Who is eligible to participate in the study?

- » English speaking, people with Parkinson disease and their care partner (couples that are in a marital-type relationship)
- » Those living in rural Alberta in an area outside of a major urban centre AND with a population of less than 10,000
- » Those who have to travel greater than 50kms to see their family physician and/or neurologist
- » Speak English

WHAT IS REQUIRED OF THE PARTICIPANTS?

Your participation will involve participating in an audio-taped conversation with a student researcher. These study visits, held at a place and time most convenient to you, may last approximately 45-60 minutes. You are free to stop the conversation at any time during the visit. All discussions will be kept strictly confidential to the researchers and study personnel involved. Your participation is voluntary and you may withdraw from the study at any time.

AMBULOSONO WALKING STUDY

Researchers at the University of Alberta are examining the effects of musical gait enhancement technology in people with Parkinson disease.

Who is eligible to participate in the study?

- » People with Parkinson disease

WHAT IS REQUIRED OF THE PARTICIPANTS?

Your participation will involve:

- » Three (3), two (2) hour in-person visits to have your physical and cognitive state assessed
- » Complete a twelve (12)-week home-based walking program using Ambulosono technology (device and training will be provided).

Contact the research project directly for more information or to find out if you are eligible to participate in any of the research projects mentioned.

Contact information is available on each individual project page on our website; visit www.parkinsonalberta.ca/callforresearchparticipants and click on your chosen research project.

WHERE DOES MY MONEY GO?

With our annual Flexxaire Parkinson Step 'n Stride right around the corner, many of you may be wondering what happens to the money you raise.

Parkinson Alberta provides almost \$2 million directly towards support services, programs, education, advocacy and research for the Parkinson's community in Alberta. With no consistent funding sources (including government), Parkinson Alberta relies on the generosity of donors, grants, memberships and of course, fundraising initiatives like the Step 'n Stride to provide the necessary funds.

It is with pride that we can report our Client Services account for the largest portion of our expenditures. Our core services, which we offer at no cost to those who require it, include individual and family supportive counselling, home visits, support groups, educational opportunities, referrals, in-services and community awareness programs. We currently offer an astounding 42 support groups across the province; and in 2015 provided over 10,000 hours of one-on-one and family support!

We offer information about the symptoms of PD, treatments, side effects, management strategies, research, community resources and navigating the health care system to individuals and health professionals. We also offer a variety of programming across the province at the lowest costs possible to participants thanks to the funds we raise at Parkinson Step 'n Stride and throughout the year.

Parkinson Alberta also looks ahead to a brighter future for those with Parkinson disease by earmarking 10% of our gross revenues to research. Whether it is a cause, more effective treatments, complimentary therapies or, ultimately, a cure; Parkinson Alberta has always been committed to research.

Rest assured, every dollar raised for Parkinson Alberta at our Step 'n Stride and other fundraising events goes towards better days and brighter futures for Albertans affected by Parkinson disease!

Consider This:

- » **\$5** = one Parkinson's info package
- » **\$25** = one hour of supportive counselling
- » **\$50** = one Parkinson's presentation/in-service
- » **\$100** = one month of access to our toll-free PD Helpline
- » **\$500** = honorariums for 2 educational speakers
- » **\$2,500** = one support group for a year
- » **\$5,000** = a summer student for research
- » **\$50,000** = a research fellowship for a year
- » **\$75,000** = a one-time research grant

Thank you for taking the time to help us raise the funds necessary to keep Albertans living well with Parkinson's!

We'll see you this September 10 & 11 at the 2016 Flexxaire Parkinson Step 'n Stride!

SUPPORT GROUPS

While many of our Support Groups run monthly, September through June, some do run year-round or have summer dates. Please check your Regional section of our website for the most up-to-date information.

ALBERTA		1-800-561-1911
TELE-SUPPORT GROUP		
3 rd Thursday of the month	10:00 am – 11:30 am	Advance registration is required to receive call-in instructions & a passcode; call the above number.
CALGARY REGION		403-243-9901
AIRDRIE		
3 rd Monday of the month	10:00 am – 11:30 am	Cam Clark Ford – 1001 Highland Park Blvd
CALGARY		
1 st Monday of the month	10:00 am – 11:30 am	Hope Lutheran Church – 3527 Boulton Rd NW
1 st Thursday of the month	10:00 am – 11:30 am	Hope Lutheran Church – 3527 Boulton Rd NW
2 nd Monday of the month	10:00 am – 11:30 am	McDougall United Church – 8516 Athabasca St SE
3 rd Monday of the month Care Partners	1:30 pm – 3:00 pm	PA Calgary Office – 102, 5636 Burbank Cres SE
4 th Monday of the month	10:00 am – 11:30 am	McDougall United Church – 8516 Athabasca St SE
4 th Monday of the month - Young Onset	7:00 pm – 9:00 pm	Hope Lutheran Church – 3527 Boulton Rd NW
COCHRANE		
2 nd Thursday of the month	10:00 am – 11:30 am	St. Andrew's United Church – 128 – 1st St E
NANTON		
4 th Thursday of the month	10:00 am – 11:30 am	St. Cecilia's Catholic Church – 2308 – 19th St
EDMONTON REGION		780-425-6400
CAMROSE		
2 nd Wednesday of the month	3:30 pm – 5:30 pm	St. Andrews Anglican Church – 4713 – 50 St NW
EDMONTON		
1 st Wednesday of the month - South	1:00 pm – 3:00 pm	Rutherford Heights – 949 Rutherford Rd
1 st Thursday of the month Care Partners	10:00 am – 12:00 pm	PA Edmonton Office – 11209 – 86 St NW
3 rd Wednesday of the month - Central	7:00 pm – 9:00 pm	PA Edmonton Office – 11209 – 86 St NW
3 rd Friday of the month - North	10:00 am – 11:30 am	Shepherd's Care – 12603 – 135 Ave
4 th Wednesday - Young Onset	6:30 pm – 8:30 pm	Call for location
FORT SASKATCHEWAN		
4 th Tuesday of the month	1:00 pm – 3:00 pm	Pioneer House – 10102 - 100 Ave
SHERWOOD PARK		
2 nd Tuesday of the month	1:00 pm – 3:00 pm	Bethel Lutheran Church – 298 Bethel Dr
SPRUCE GROVE		
4 th Thursday of the month	6:30 pm – 8:30 pm	Pioneer Centre – 301 Jespersion Ave
ST. ALBERT		
3 rd Tuesday of the month	1:00 pm – 3:00 pm	St. Albert 55+ Club – 7 Tache St
WESTLOCK		
Last Monday of the month	1:30 pm – 3:30 pm	Room 140, Provincial Bldg – 2, 10003 – 100th St

GRANDE PRAIRIE REGION		780-882-6640
GRANDE PRAIRIE		
2 nd Tuesday of the month	2:00 pm – 4:00 pm	Wildrose Manor – 9358 – 70th Ave
3 rd Monday of the month	1:00 pm – 2:30 pm	PA Grande Prairie Office – 103, 10901 – 100th St
Care Partners		
LETHBRIDGE REGION		403-317-7710
LETHBRIDGE		
3 rd Thursday of the month	2:00 pm – 3:30 pm	Lethbridge Senior Citizens Org. – 500 – 11th St S
RAYMOND		
3 rd Tuesday of the month	2:00 pm – 3:00 pm	Prairie Ridge Centre – 328 Broadway S
TABER		
2 nd Tuesday of the month	10:00 am – 12:00 pm	Taber Public Library – 5415 – 50 Ave
LLOYDMINSTER REGION		780-808-5006
BONNYVILLE		
Aug 23 – future dates TBD	Please call	Bonnyville Healthcare Centre – 5001 Lakeshore Dr
LLOYDMINSTER		
Oct 3 - Care Partners	1:30 pm – 3:30 pm	Meridian Building – 5120 – 48 St
4 th Tuesday of the month	2:00 pm – 4:00 pm	Southridge Community Church – 5701 – 41 Street
WAINWRIGHT		
1 st Wednesday of the month	7:00 pm – 9:00 pm	Provincial Building – 810 – 14th Ave
Care Partners		
2 nd Tuesday of the month	2:00 pm – 4:00 pm	Provincial Building – 810 – 14th Ave
MEDICINE HAT REGION		403-526-5521
MEDICINE HAT		
1 st Tuesday of the month	1:00 pm – 3:00 pm	Ricky's All Day Grill – 910 Redcliff Dr SW
Care Partners		
2 nd Wednesday of the month	1:00 pm – 2:30 pm	PA Medicine Hat Office – 101, 928 Allowance Ave
Men with PD		
3 rd Tuesday of the month	10:30 am – 11:45 am	Chinook Village – 2801 – 13 Ave SE
4 th Tuesday of the month	1:30 pm – 3:30 pm	Crossroads Church – 1340 – 22 St SE
4 th Wednesday of the month	1:00 pm – 3:00 pm	Ricky's All Day Grill – 910 Redcliff Dr SW
Women with PD		
RED DEER REGION		403-346-4463
CASTOR		
Sept 20 & Nov 22	1:30 pm – 3:30 pm	Paintearth Lodge – 4501 – 55 Ave
INNISFAIL		
1 st Wednesday of the month	1:30 pm – 3:30 pm	Church of the Nazarene – 4904 – 48 St
LACOMBE		
4 th Wednesday of the month	1:30 pm – 3:30 pm	Wolf Creek Community Church – 4110 Hwy 12
OLDS		
2 nd Wednesday of the month	1:30 pm – 3:30 pm	Sunrise Village – 5600 Sunrise Cres
RED DEER		
3 rd Wednesday of the month	1:30 pm – 3:30 pm	Davenport Church of Christ – 68 Donlevy St
THREE HILLS		
Oct 4 & Nov 29	2:00 pm – 4:00 pm	Community Drop In Centre



Get Involved

WALK AS A TEAM

Gather your crew and join us September 10 and 11 at one of our TEN 2016 Flexxaire Parkinson Step 'n Stride Walk locations! It is a great way to spend your weekend with family & friends; or perhaps you have a group of coworkers who wish to form a company team. Joining or forming a community or corporate team is the best way to experience the Parkinson Alberta Step 'n Stride. Get involved, walk as a team.

It takes two to make a team and you can be creative with a name and theme. Some clever team name ideas to inspire your team name include:

- » Sole Sisters
- » Dudes got Running Shoes
- » Walk this Way
- » The Fab Four

If your team wants to stand out in the crowd pick a theme and dress the part. Create excitement and have fun by designing your own walk t-shirts, wearing crazy hats or sunglasses, or put some bells on your shoes. Take your team back to the future with a disco 70's costume, legwarmers and headbands from the 80's, or a neon 90's team.

Team registration is easy, register for your walk location and start fundraising today! Parkinson Alberta offers easy online registration and pledge tracking. By using the online system, you help us reduce administrative costs and maximize funds directed to support services and research.

If the online system isn't for you, you can still complete a paper registration. Forms are available for download at www.parkinsonalberta.ca/stepnstride, or from any Parkinson Alberta office.

This September 10 & 11, join us and over a thousand individuals, their families and teams across the province at the only walk dedicated to making a difference in the lives of Albertans affected by Parkinson's.

Don't forget to use the hashtags **#StepNStride** and **#WhyIWalk** when posting on **Twitter, Facebook or Instagram**

Like us on



Facebook.com/
ParkinsonAlbertaSociety

Follow us on



@ParkinsonAB

Share a Moment with



instagram.com/
parkinsonalberta



Last Look JOIN TEAM ALBERTA AT #WPC2016

More than 3,500 people from 65 countries will attend the 2016 World Parkinson Congress (#WPC2016) in Portland, Oregon this September 20-23 to learn about cutting edge science, clinical research and comprehensive care in Parkinson disease from some of the most renowned health professionals, researchers, and advocates globally.

There are so many ways to learn more about all the different aspects of Parkinson disease. From information on the disease itself, to research, to topics that cover the various ways to live well, and so much more. You can watch videos and webcasts, stop at your local library or book store, and visit your regional Parkinson Alberta Office, just to name a few. So why consider attending the 2016 World Parkinson Conference (WPC) in-person?

Here we list five reasons to attend #WPC2016!

- 1. It's a pretty big world, but you are NOT ALONE!** With today's technology it is easy to connect with people around the globe; but there really is no substitution for being able to get together with people face-to-face. Attending #WPC2016 is a chance to discover that you are not alone in aiming to live well with Parkinson's; there is a world full of people who understand.
- 2. Break Out of Your Comfort Zone** Apathy is one of those non-motor symptoms that is often hard to acknowledge and/or recognize. It is a symptom that can lead not only to isolation, but depression and anxiety as well. While there are those who like to "shake things up" (pardon the pun), for many with Parkinson disease new events, can be a challenge. However, breaking out of your comfort zone can be just the type of action necessary to keep apathy at bay.
- 3. The Options are Many and Varied** Hot Topic presentations, plenary speakers, roundtable workshops, sessions, networking and social events are just a few of the multitude of opportunities available to you at #WPC2016. Tailor your experience to suit your interests and needs.
- 4. Take Charge of Your Life** Attending #WPC2016 is an investment in living well with Parkinson disease. It is an investment in yourself, your loved ones, and in your life with Parkinson's. It is an acknowledgement that you are not your disease, that there are still things to learn, and that you are worth it.
- 5. Have Fun!** A good conference will help you grow and challenge yourself; a great conference will also be a fun and meaningful experience. The 2016 World Parkinson Conference is a great conference, providing a unique convergence of learning, networking and fun!

Visit our website (www.parkinsonalberta.ca/wpc) to register or to view the Provisional Program so you can see what is happening and what sessions are available to you at #WPC2016.

Parkinson Alberta invites anyone planning on attending WPC 2016 to also register with Team Alberta and be a part of our Alberta delegation! Twenty people have already let Team

Alberta know they will be heading to Portland! As Portland is so close, many of them have decided to turn this into a fun road trip as well!

If you are planning on attending or would like more information please call **780-425-6400** or email communications@parkinsonalberta.ca

sip sample support

sip sample support –
an evening of
hope and travel

Medicine Hat
Friday, October 21

sip sample support –
a taste of the
market

Calgary
Saturday, October 22



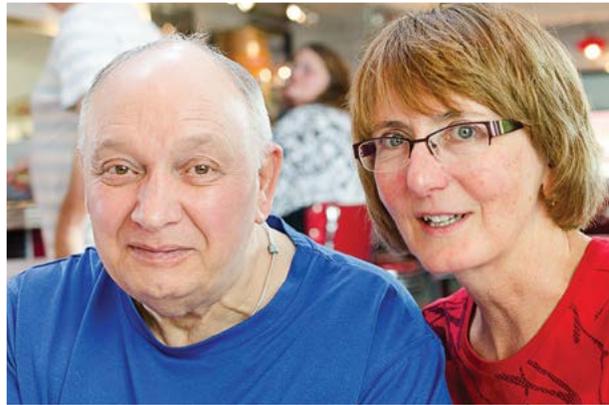
September 20 - 23, 2016

Join
TEAM ALBERTA
at
#WPC2016

Parkinson
Alberta

FOR MORE INFORMATION ABOUT ANY OF OUR
EVENTS OR TO PURCHASE TICKETS, PLEASE VISIT
WWW.PARKINSONALBERTA.CA

Call 780-425-6400
to register



SEPTEMBER 10

CALGARY
North Glenmore Park | 9:00AM

EDMONTON
Rundle Park | 9:00AM

GRAND PRAIRIE
Muskosepi Park Pavilion | 10:00AM

LETHBRIDGE
Indian Battle Park | 10:00AM

LLOYDMINSTER
Bud Miller Park | 9:00AM

RED DEER
Golden Circle | 9:00AM



SEPTEMBER 11

BONNYVILLE
Little Leap Park | 1:00PM

CAMROSE
Mirror Lake | 1:00PM

COCHRANE
Cochrane Rancho Historic Site | 12:00PM

MEDICINE HAT
Crescent Heights High School | 10:00AM

REGISTER TODAY

parkinsonalberta.ca/stepnstride