

Parkinson

PULSE

Connecting people living with Parkinson disease in Alberta



THE POWER OF ONE



**LIVING SOLO
WITH PD**



THE ZONE

A DOCUMENTARY OF RESILIENCE AND DETERMINATION

EVENT & RECEPTION

SATURDAY, APRIL 29
12-3 PM
CARDEL THEATRE
CALGARY

SUNDAY, MAY 7
6-9 PM
METRO CINEMA
EDMONTON

The Zone follows Rob Wood from his home on Maurelle Island to Mount Van Der Est; the mountain he never thought he would climb again. Along with some of Canada's most amazing mountaineers, Rob shares his journey with us as he attempts to pull off one last climb, while dealing with Parkinson disease.

VISIT
WWW.PARKINSONASSOCIATION.CA
TO PURCHASE TICKETS





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Spring 2023

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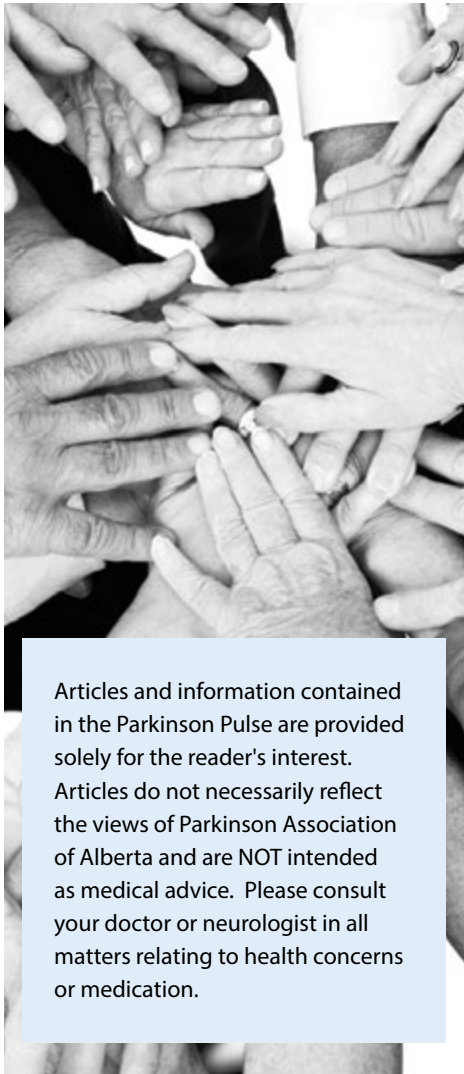
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Parkinson Association of Alberta is the source for support, education and inspiration for people impacted by Parkinson disease and Parkinson's Plus Syndromes, and engagement in important quality of life research with an emphasis on Alberta.



Articles and information contained in the Parkinson Pulse are provided solely for the reader's interest. Articles do not necessarily reflect the views of Parkinson Association of Alberta and are NOT intended as medical advice. Please consult your doctor or neurologist in all matters relating to health concerns or medication.

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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SAVE
THE
DATE

Saturday, May 23 @ 11am
Virtual meeting with an in-person option in Calgary



2023
ANNUAL
GENERAL
MEETING

Be sure to purchase
your membership by
April 29 in order to vote



Message from our Executive Director

Dear friends,

The arrival of spring brings the anticipation of warm weather, green growing things, and a general relief from the challenges of winter in Alberta. I hope this edition of Pulse finds you well.

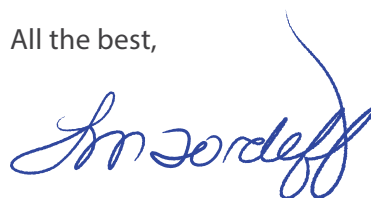
I don't think there's been a day in the last six months where one or more of our team hasn't been out sick with some manner of cold or flu. This meant all hands-on deck and so we thank you for your patience and support when a person you weren't expecting showed up at a group or one of us fumbled through an unfamiliar phone request. For me, these opportunities are an important reminder of why this organization exists. Which also led us to the theme for this April's Parkinson's Awareness Month: **Celebrating Our Community.**

Dictionary.com has nine unique definitions of community that group by religion, culture, interests, geography, etc. The one I think best relates to our Parkinson's Community is "a group sharing common characteristics or interests and perceiving itself as distinct in some respect from the larger society within which it exists". I think we can all agree that this is not a community that people are clamouring to be a part of. Our shared interest is a disease. What makes us distinct is a disease. But it's not just the disease that makes us a community. Whether you are a person living with a PD diagnosis, a care partner or family member, a health

care provider, a researcher, educator, or donor, you have a genuine interest in helping and in seeing people live well and feel connected, valued, and valuable. You play a part in improving the day to day lives of people affected by Parkinson disease. You are part of a caring community of support, and I think that's worth celebrating. Please join us for the various educational and social activities planned for the month of April and celebrate our Parkinson's Community with us!

This edition of Pulse focuses on the solo Parkinson's experience and speaks to those in our community living with this disease on their own. The information and resources may also be helpful to those living with a partner who travels frequently or who is themselves, living with disease. The Community concept is increasingly important for people without consistent, reliable access to help. We hope you will find some meaningful guidance in the pages that follow and if you haven't already, please also consider including us in your community of support. Our team is eager to hear from you to help get you started.

All the best,



Lana

Cover Story

THE POWER OF ONE



**LIVING SOLO
WITH PD**

Written By: Brandi La Bonte

**AHH THE SINGLE LIFE.
DOING WHAT YOU WANT,
HOW YOU WANT AND
WHEN YOU WANT TO.**

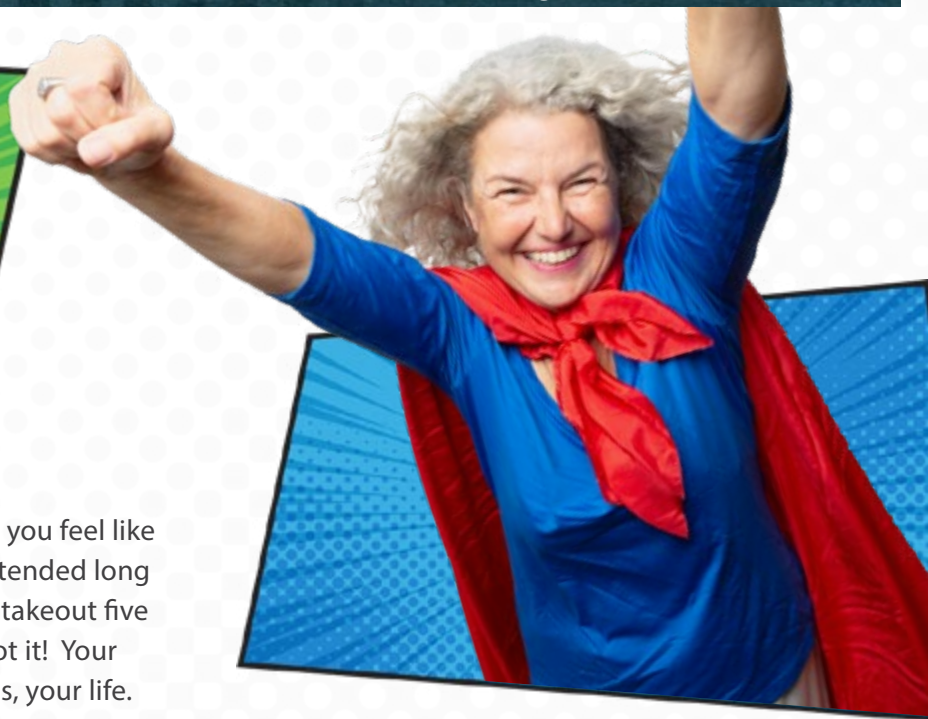
Buying that new gadget or pair of shoes because you feel like it? Yes, please! A trip to Mexico or Paris for an extended long weekend? Bags are already packed! Dine in, get takeout five times per week, or have cereal for dinner? You got it! Your shows, your music, your timetable. Your decisions, your life.

By choice or by chance, for many individuals living solo means freedom and independence. A caution though, it can also mean isolation and loneliness if one isn't mindful. Millions of individuals around the world live happy, fulfilled lives as single, independent human beings. They have rich personal and social connections, and participate in the world in meaningful and purposeful ways. But having a good life does not make one impervious to illness and disease; and when illness strikes, it can seem scary and daunting especially when one is single. Potentially even more so when that illness is Parkinson's, a progressive disease.

Not much research has been done on the solo Parkinson's experience. Maybe that is because the disease itself remains the same; it is life with the disease that is different. In a lot of the literature out there on Parkinson's disease management (especially later on in the diagnosis) much emphasis is put on leaning on one's partner/spouse/care partner for help and support. And while this is absolutely beneficial for many, it doesn't really help when one is riding solo.

So can one have solo Parkinson's AND live a life as happy and fulfilling as their coupled up peers? The answer is a resounding YES!! It's just going to take a little more preparation and planning.

Throughout this issue you will find valuable perspectives, information, and tips to help one manage Parkinson's as a strong, independent single person. From planning ahead to dipping one's toe into the dating pool, we've got you covered. Consider the Staff at PAA your "plus one", we'll be there for you whenever you need us.



Alone, NOT Lonely

Combating Isolation in Solo PD

Written by: *Brienne Leclaire*

Managing Parkinson's alone can be an isolating experience. Isolation is not an uncommon occurrence. Studies have shown that one in six adults feel isolated either socially or geographically and 25% of people over the age of seventy feel isolated. Isolation increases our risk for certain health conditions such as stroke and high blood pressure while also having significant impacts on our mental health such as increasing our risks for depression, apathy, and anxiety. Being isolated also impacts our general feeling of well-being and we see this popping up in different Parkinson's symptoms. These include increased fatigue, increased apathy, insomnia, increased muscle tension, headaches and body aches, and increased feelings of loneliness or sadness.

One of the most important things that we can do to combat isolation is building ourselves a routine. Making a routine for your day will look different for everyone depending on your needs and schedule. Apathy is common in Parkinson's and can make it harder to maintain a routine and keep up with daily tasks. Routine helps build structure in our lives including all the activities we do daily. If there are other activities you do less frequently you can build those into your routine as well.

Meaningful social connections are so important for reducing feelings of isolation. Staying connected with those in our circle and connecting with other people in our communities helps us feel less alone. Social connections might look like going over for family dinners, meeting with friends, spending time with friends and families doing activities and going out into the community. It can also be making phone calls to friends and family or connecting digitally like on zoom or skype. Another option is connecting with people over social media where we can connect with people with similar interests.

We can also make meaningful social connections by getting out in our community. You can join a group, club, or a community organization. This is a fantastic way to get out and join things that connect you with people with similar interests and build social connection. You can attend a support group like the support groups we run here at Parkinson Association of Alberta. We run support groups all over the province with options for in person and virtual groups. You can also make social connections by volunteering. There are always wonderful organizations looking for volunteers in a bunch of different capacities. Volunteering helps us help other people and give back to our communities giving us a sense of pride and purpose.

Participating in hobbies can help us combat feelings of isolation. Hobbies look different for everybody; you might have a hobby that you have done for a long time, or you might be starting something new. It could be gardening, crafting, knitting, golf, fishing, or all kinds of different hobbies. Hobbies help to keep us busy making us feel less isolated and more fulfilled. We can also take advantage of things like getting connected with different groups that also take part in these hobbies. Joining a community group, or online group on social media like Facebook. Social media has different groups dedicated to hobbies. These groups are where people share their hobbies, their expertise and ask questions about them. Local community centres and seniors' centres often have hobby clubs that people can get involved in as well. Bringing the socialization and community aspect to often individual hobbies.

Consider learning something new. Lifelong learning not only helps our cognitive abilities stay sharp, but also helps us engage with others. Having an expansive knowledge base can help us in our social life by connecting with people in more diverse ways. There are many ways to learn and engage our brain in things like reading, listening to a podcast or an audiobook, watching documentaries, learning a new skill or language. Anything that helps us expand our knowledge and skills can help us engage our brain and in turn make us feel more connected.

Next up we have exercise! When we exercise, we feel good, it helps us increase our energy levels and promote good health. Exercise can be anything that gets your heart rate going and exerts energy. When we feel better about ourselves, we feel less isolated and feel more comfortable to get out there and socialize. Exercise can also be a social activity if you engage in it with a group. It is something that can help combat isolation and make us feel better overall. Hand in hand with exercise is getting outdoors. This can be getting outside for a walk, working in the garden, or even just sit out on the deck or in your yard and enjoy the sun. Getting fresh air makes us feel better and improves our overall health which in turn reduces isolation.



The last tip is to practice self-care. Think about all the activities that we do that help us take care of ourselves, this is self-care. All the things mentioned in this article fall under self-care. Odds are there are many other things that you already do to take care of yourself that make you feel better, increase your feelings of well-being, and promote overall health. Some examples are scheduling regular doctors' appointments, eating healthy, getting enough sleep, taking medication properly, doing personal care like bathing/showering. Activities that improve our sense of well-being and self also fall under self-care. These could be things like meditating, doing yoga, practicing breathing exercises, attending spiritual or religious services, and being connected to something bigger than ourselves.

There are many ways we can combat isolation and how we do so will be unique to who we are as an individual. Finding what works for us takes some trial and error. Do not be afraid to step out of your comfort zone and try something new. If you take anything away from this list, take away that combating isolation is accomplished in two parts. Taking care of ourselves, so we feel good, AND connecting with others around us.

One Step at a Time

Managing Care Solo

Written by: Alana Wright



Managing care is extremely important, especially when living independently as we rely on this to remain healthy and to be at home safely for as long as possible. So, what is included with managing care? This can be a variety of things such as medications, personal care, hygiene, exercise, and overall well-being. Managing care can be overwhelming but we're here to help. Let's break it down!

Medications

Taking medications on time is extremely important, but sometimes it can be difficult to remember to take them on time on your own. There are some simple answers. First, you can consider using a smartphone pill reminder app to help you take your medication or set an alarm for the times during the day when you need to take medication. However, we know this doesn't always work for everyone. A couple of other options could be having your medications placed in bubble packs by a pharmacy, using a pill timer cap that tells you what time you last opened the bottle, or if you're not into the technology craze, an old school digital watch with multiple alarms can also do the trick! (Thanks to Hugh C. for the watch idea!)

Not only is it important to know when to take your medication, but it's also important to know what you are taking. Making a list of your medications noting times, the dosage you take, and any side effects can be valuable to have for several reasons. Additionally, you want to record any supplements or over the counter (OTC) medications such as Advil, Tylenol, or even antacids that you may be taking. Sometimes supplements or OTC medications can cause serious

side effects or interact with medications that you may be taking or could be given, so it's important to have this noted. The Aware in Care Kit that comes with a Parkinson Association membership has a handy notepad that can be used to record your medications and has multiple sheets so you can distribute these to your pharmacists, doctors, or any other healthcare professionals as needed! This is a great way for you to keep track of your medications if you're on your own.

Next, if possible, have all your prescriptions filled at one pharmacy. A pharmacist can ensure that you aren't at risk to any potential drug interactions if they have all the information regarding your medication. However, if you must use more than one pharmacy for any reason, be sure that you are providing updates about the medications you're currently taking to both pharmacists to ensure they have access to this information so they can best support you! Don't be afraid to ask your pharmacist any questions you may have about your medication either! They are there to help and are more than willing to sit down with you and answer any questions you may have.

Creating a Safe Environment

We all want to stay at home for as long as possible, but safely managing that may require some adjustments or modifications to your home. Changing your home can be intimidating or difficult and, in some cases, costly. The good news is that there may be financial help available and/or practical, but affordable solutions. By making sure the environment you live in is safe, you are prolonging your independence, providing yourself autonomy, and mitigating the risk of injury.

And when your mobility starts to change, keeping your residence comfortable and accessible will not only allow you to stay at home longer, but also safely. So, what modifications can you get for your home? Modifications can include things such as grab bars in the shower, bed railings, ramps to avoid or minimize the use of stairs, or adjusting the hinges on doors to allow them to open further or in a different direction to create more room. When you're flying solo, it's important to create a safe environment early on as it can take some time to implement some of these modifications.

Location, Accessibility, and Transportation

It's important to start thinking about your home's location, accessibility, and method of transportation early on, especially if you live in a rural or suburban area that requires a lot of driving. If you're on your own and no longer able to drive do you have a means of transportation? Or would it be more beneficial to live somewhere that has sufficient access to public transit? It's important to take as much into consideration as possible. How much time it takes you to get to services such as shopping or medical appointments? Would it be worth it to consider a move that would give you more freedom through public transportation? Sometimes it can feel like we are thinking way too far into the future, but when you're on your own you want to be prepared early on. This way you can ensure that you have the most autonomy in your life and allow yourself the opportunity to explore all your options thoroughly.

Homecare, Socializing and Programs/Activities

When living alone, homecare is extremely important, especially if we want to stay at home for as long as possible. However, it can be hard to figure out if you need homecare, what services you might need from homecare, and how much time of homecare you may need. If you're ever unsure, you can always put in a request for an assessment. By doing so, you can meet with an occupational therapist or registered nurse to explore your options and provide you with their recommendations.

Isolation can be a major cause of emotional distress for single seniors, so it is vital to create opportunities for socializing! There are so many fantastic programs

out there that are eager to have you be a part of them! Finding a program that matches your interests or even looking into local day programs can be a great way to meet people and stay connected. I know it can be a little scary going into something new where you might not know people or what to expect. That's okay! The great thing about a lot of these programs is they might let you observe or do a trial run before signing up depending on the program. This is a great way for you to experience the possible benefits of programming without having to commit right away. By doing this, you can get a sense if the program is a right fit for you, ease some of the nerves you may have about joining, and above all else, meet new people and possibly develop some life-long friendships!

Planning your Finances and Investigating your Options Early

It's no secret that higher levels of care such as assisted living or in-home care can be expensive. Consider making a budget with anticipated expenses early on to help you evaluate the pros and cons of your situation and determine what's the best route for you in the future. By exploring your options early, you can find one that is right for you when the time comes. When you're on your own, you are your own advocate. By investigating options early and determining what you want, you can ensure that down the road your wishes are fulfilled! It'll allow you to take control over your future and give you the power to make the best decisions for yourself.

It's normal to feel confused, vulnerable, or even frustrated when you realize you may not be able to do the things you used to be able to do. Different feelings might arise such as feeling guilty about asking for help or feeling uncomfortable having "strangers" in your home. By acknowledging these feelings and talking about them it can help you manage your feelings and cope with the changes. If you have an open mind and a willingness to try new things, you may be able to prolong some aspects of your independence for longer!

Finally, be patient with yourself and give yourself grace. Changes are a typical part of aging and although shifts in your level of independence can be frustrating at times, sometimes new experiences and situations can lead to developing new friendships or discovering new possibilities!

Flying Solo

An Interview with Olenka Melnyk

Interview by: Declan Beddow



Throughout this issue of Pulse magazine, we have been addressing topics that pertain to a unique group of individuals with Parkinson disease; those who are single and/or live alone without a primary care partner to rely on as they navigate this journey. In this article we get a firsthand account of what it is really like to fly solo with Parkinson's. The delightful and thoughtful Olenka Melnyk agreed to sit down with us and share her first-hand insights on managing Parkinson disease solo. Quotes have been modified for brevity.

Declan Beddow (DB): Could you please introduce yourself.

Olenka Melnyk (OM): My name is Olenka Melnyk. I'm 71 years old and have been retired for six years. I've worked as a writer and an editor for many years. I've lived in Edmonton for a long period of time, and I've got two grown children who both live in Edmonton as well. I was diagnosed with Parkinson's about a year ago, but I've had symptoms for much longer than that.

DB: We're here today to talk about Parkinson's as a single person or someone living alone. So, how are typical challenges approached differently in your situation?

OM: Parkinson's is challenging in any case, but I think it's particularly challenging when you live alone because you basically are responsible for yourself,

including day to day things, running a household finance, looking after yourself, socializing planning, and going to medical and therapy appointments. There isn't somebody to drive you, take you there, make the meals, clean up the house, and organize things. So, it is more challenging and there is always the fear, and the vulnerability, that comes as the condition progresses. The future can become more frightening because you must have a backup plan, and how do you make a backup plan when Parkinson's is so unpredictable? So, there is all the same responsibility, but there isn't that one person that kind of has your back.

DB: How has your family and social relationships changed since you've received your diagnosis?

OM: Well, it changes how I function overall as a person. I've been fortunate to enjoy what I call "mindless good

health”; to have had good energy and be active. It gave me a great deal of pleasure to be helpful to the people around me. This changes with Parkinson's. Your energy levels go down, your ability to focus, and do things. I'm not the one doing all the cooking for Christmas dinner anymore.

I think part of it is trying to educate and prepare my family. This is what Parkinson's is all about. Here's where I'm at. Try to be honest with what I'm capable of doing at a particular time and let them know how these things have changed.

It has shifted the balance quite a bit. And I think, like many people at my age, I'm finding that many of my friends are also dealing with health issues. Suddenly for many of us here, we're dealing with health issues and surgeries or chronic illnesses, and our aging all at the same time. So that changes the relationships a great deal and how you can rely on people. I think that has also forced us to dig deeper in our friendships and family relationships because you have to be honest with where you are, let each other know about your vulnerabilities, and kind of open up your heart more. For me it's been a big issue about how to be able to receive help and feel like your dignity is still intact and you're worthy of this. That you're not overburdening people.

DB: How does planning for the future look different for you?

OM: Well, I go after the bottom line. That's my way of dealing with issues when they come up. So, after I found out that I had Parkinson's, I immediately started looking up end of life care and provisions. My GP (general practitioner) watched me, and she says, you know, Olenka, this is a little bit premature. You've probably got a couple more years of a good kick at the can. She didn't quite phrase it that way, but I kind of went to the end of the road scenario, which I actually found very comforting to do. It made me feel better to go for the brutal, brutal planning.

Part of it is looking around and asking: how can I live independently as long as possible within my home?



But deciding when not to push it too far. Because if I'm pushing it too far, I'm not going to be capable of looking after myself and I will be a big burden for family and friends. Although I have two children in town, boy, they sure have a lot of challenges in their own lives, and I don't want to needlessly put more strain upon them.

So, it's been thinking ahead from A to Z. In essence, what can I do to make my house more livable than now? What do I do when I no longer can live there? What are the alternatives? And start to look at that. That's included, in my case, just hiring help like housekeeping, yard work, and snow shoveling. Because, physically, it's just become much more difficult to have the energy to do all those things. It's been important to me not to be afraid to look at the future. To say these things will come. They will happen. And to really try to make my children and people around me comfortable with that as well. To say to them, here's what I've planned, here's where my thoughts are, and to make it part of the normal conversation rather than something that seems morbid.

Do it while you can, while you're clear headed and then just focus on enjoying your life or going about it with as much meaning and care as you can.



DB: Can you talk a little bit more about how your perspective has changed since being diagnosed?

OM: Well, I think especially within my friendship group, it's been really dealing with our mortality, and I mean, we all have to deal with it. But when you have Parkinson's as well as other illnesses, it's there in your face. So that's been really important to share, to really find the humor about it, and to ask for help. That can be extremely difficult to do. It also means you have to let go of your ego, because our bodies are not functioning the way that we would like them to.

Sharing and remembering your values, the things that are important, and really letting go of the petty things and unnecessary things. Including in family relationships, and really making an effort to make sure my relationships are good and if there's been any misunderstandings to clear them up and just to really open your heart up.

And I'd like to just say that because Parkinson's is so unpredictable, I find that you really find a real sweetness in day-to-day life. Things become more

precious and more meaningful and it's a real gift every day. A lot of gratitude.

DB: Why is it important to talk about managing PD solo?

OM: It's beginning to change, but I still think that there's very much an emphasis on a more conventional approach to your living situation, that you're within a marriage and a family, and there's somebody there to pick up after you.

About a quarter of people over 65 are now living on their own. So, when you consider that about 100,000 people have Parkinson's in Canada, there's thousands of people who are on their own. And I think that it's really important that those particular needs are addressed.

So, you know, if you go to a support group and everybody's there with a spouse, and most people are, I mean, that's really lovely, but it kind of skews the dynamics a little. You are dealing with the same condition, but the circumstances are quite different. And it's really, really important that that be addressed, because I think when we're dealing with Parkinson's, it's really important that we all feel heard and understood. And not to feel sorry for yourself, but to really give yourself credit that you're trying and to hear from other people that, yes, this is typical, the feelings that you have are normal, and here are some ways that you can cope.

DB: Any last comments or anything you'd like to add before we wrap things up today?

OM: I'm really excited and pleased that the Association (PAA) is doing a support group for people living on their own with Parkinson's. I really welcome that and look forward to it. At this point in my life, I'm really searching for more support experience, and I'm really glad that we'll have the opportunity and to meet and talk and help each other out.

Thank you to Olenka for taking the time to sit down with us and talk through her first-hand experience living with PD solo.

PROGRAM NEWS & UPDATES

AB North & NWT Coffee Chat & Social

This is a brand new online social for people located in Northern Alberta, who would way to connect with like minded individuals, through Zoom.

Movin' & Groovin' - Dance Program (Edmonton)

Due to popular demand, Parkinson Association has brought back a dance program. This fun program is for both people with Parkinson's and/or their Care Partners and requires no previous dance experience. There are many benefits to dance, sign up for the first session that begins in May.

Parkinson Association 101 Series

These have proven extremely popular already! There are different topics coming up such as; DBS/Duodopa 101, PD+ 101, Advanced Care Planning & Government Resources 101 and PD 101. Registration is required for each session.

Occupational Therapy

The last sessions of Living with PD Series finish up in April. If you are interested in learning some tips and tools to manage Technology, Leisure Activities, Transportation or Gardening tasks, give us a call to register.

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

WHAT'S NEW?



Important Dates to Remember

All PAA Offices will be closed on the following dates:

April 7 (Good Friday)

April 10 (Easter Monday)

May 8-10 (In-Person Staff Meetings)

May 22 (Victoria Day)

July 3 (in lieu of Canada Day)

SAVE THE DATE!

September
9th & 10th



parkinsonassociation.ca



WHO ARE YOU WALKING FOR?



One LOVE

Dating & Relationships with Parkinson's

Written by: Colleen Davison

Young and bold or older and wiser, none of us are immune to the awkwardness that is dating. From wondering if you are reading the signals right, to finding the courage to put yourself out there, and decide that now is the time to ask the special someone out for a date. Then there are the “what ifs”. What if they don’t like me? What if they don’t like dogs? What if I say something silly? What if I never find someone? Add Parkinson disease into the mix and the what ifs can get out of control. What if? What if? What if?

What ifs...we all have them, (or have had them) especially when it comes to dating. Possessing the vulnerability required to approach someone or go out on that first date is not for the faint of heart!

Vulnerable feelings stem from your core belief about who you are, what you want, your self-worth, health concerns, and even prior dating/ relationship experience. Being vulnerable can be very scary. Now I have a new what if to consider. What if I’m scared, but I try anyway?

Let us not be thwarted by fear or regret, but let us shoot beyond mere stars, let us bask in all the splendor with unapologetic enthusiasm.

In this article we will explore conversations around dating/relationships and Parkinson’s. Dating can be an exhilarating experience. Once the ice is broken,

you’ve made the initial connection, dating is exciting and something to look forward to. Or is it? Introduce Parkinson’s and the entire outlook can feel very different, like your life is somehow unmoored because of a Parkinson’s diagnosis.

Let’s look at a few questions people struggle with before embracing the moment and entering the dating/relationship world.

What would I say if my date notices I have a slight tremor, but I’m not ready to disclose I have PD?

Conversations around Parkinson’s start with your personal boundaries. As an emotionally healthy, mature, autonomous individual, it is not your responsibility to meet someone else’s expectations. Although over time the requirements of a relationship will change, remember in this conversation we are talking about meeting and dating someone new. You do not have a responsibility to disclose every aspect of yourself to someone with whom you’ve just met, you have not established trust, or even friendship. Let’s look a little further.

When we force ourselves to be transparent before our personal readiness, we may be engaging in “people pleasing behaviours”. This means we ignore our base

instinct to protect ourselves and keep ourselves safe; it's self-sacrificial; learned patterns of behaviour. You make yourself boundlessly available and demonstrate pleasing interactions because you want this person to like and accept you. These feelings/patterns are learned, unfortunately positive outcomes when we are self-sacrificial in new relationships are rare. An imbalance of power is created. Remember, we teach people how to treat us in how we respond to things, whether in our best interest or not.

Another possibility is you might disclose before your personal readiness as a way of unconsciously sabotaging the potential for something more. People will sometimes make shocking statements or over share personal details as a way of proving to yourself that, in this case, having PD means the end of all dating, no hope of finding love or companionship. That response mechanism comes from fear. Fear of rejection, fear of judgment, abandonment and so forth. In this scenario, I would suggest reaching out to a professional that can help you create boundaries that create safety for you as you navigate healthy beginnings in your dating activities. Knowledge is power.

When is the right time to tell the person I date, that I have PD?

I believe this to be a pinnacle question, with a clear and linear answer. The answer is: when you feel that the relationship has reached a place that feels safe, and you feel you can trust this person to fairly and thoughtfully weigh the information set before them. It's fair to take your time, establish trust and then share details about living with PD. It is equally fair for your person to take their time in processing this information; any relationship requires both people understanding the commitment they are making. These conversations may feel difficult and scary. I suggest undertaking them when and only when you trust this person will demonstrate integrity and kindness in everything you share.

Is it all right not to disclose I have PD? Asking for a Friend

A successful relationship is built on trust, love, and respect. Part of the responsibility we have is to respect our person enough to give them the tools they need in making informed decisions for themselves. Engaging in a serious monogamous relationship,

not casually dating, but a meaningful relationship, and not disclosing you live with PD is not likely to end well. Your partner will eventually find out, and now you have trust issues; secret keeping. This type of secret is often experienced as a betrayal. This is a slippery slope fraught with poor outcomes. Another thing to consider, as the secret keeper how will you feel knowing this secret is yet undiscovered. Will you be the best version of yourself living with this secret? How would you feel if it was your partner who kept secrets/important information from you?

The same principle applies to friends and family of your new partner. Together you will fine tune the inner workings of your relationship and discuss your feelings about sharing PD with friends and family. Guided by your feelings, this is your body your condition. You guide your partner in the way that is the most comfortable for you. A loving and respectful partner will hold space for that.

Can I still have children with young onset Parkinson's?

This is an important conversation especially for those with young onset PD. From a physical perspective, women with Parkinson's have not been identified as having issues with fertility, conception, and birthing. Studies have indicated that having Parkinson's should not exclusively determine the delivery method (vaginal birth vs cesarian section) and that birthing under the support of a qualified medical professional is safe. Considerations about medication, contraindications, or other risk factors would be identified individually by your treating medical practitioner, not unlike a woman without Parkinson's.

Decisions around childbirth should be made with your partner and your medical health professional. Men with young onset PD may also be able to conceive naturally depending on symptoms; even where there is erectile dysfunction. Medications maybe discussed with your medical professional to assist you with functional issues.

The success of your relationship will be determined by the extent to which both parties' needs are served. Always turn towards each other in times of uncertainty. Turning towards your partner reassures them you are present and committed. We need to be intentional when building these connections. Those are the relationships that transcend all other things.



I am **ONE** but we are **MANY**

A Solo Discussion on Parkinson's

Written by: Emma Torneiro

The initial diagnosis of Parkinson disease (PD) or a Parkinson's Plus Syndrome can create new challenges and disruptions to your daily living and efforts of future planning. As the disease progresses, these challenges may change or increase, leading to new fears about living with Parkinson's. As Client Services Staff we speak with and get to know a lot of different people across the province. We learn about their challenges and concerns as well as their hopes and joys. We are also able to identify areas where more thought, support and/or education might be needed. One of those recently identified areas has been the unique concerns of managing Parkinson disease solo.

We understand there are always new challenges with the disease, but we also know those managing Parkinson's on their own have additional hurdles to overcome. This is where the idea for this issue of Pulse came from. For my article I sat down to talk with a group of solo members in our Parkinson's community to better understand these difficulties and brainstorm potential solutions to living well with solo PD.

The first challenge identified focused on concerns of isolation and mental health with a chronic condition. And the difficulties that can come with having no partner to brainstorm with or bounce ideas off of, provide support with decision-making processes, or engage in conversation with an understanding of the unique aspects of the disease. Having to face

this unpredictable disease alone and struggling to navigate the uncertainty can leave a person feeling overwhelmed, isolated, lonely, sad, or even angry.

Parkinson Association of Alberta is always here to make sure you never have to walk alone with your disease. We're always just a phone call away with a listening, empathetic ear. We understand the importance of maintaining social connections and prioritizing your mental health. We encourage staying connected to friends, family, and local supports. For example, joining a support group or calling a friend to check in. According to one of our members, being open to accessing supports and engaging in open communication regarding challenging topics can help you realize you're not alone because connections can ease the journey with Parkinson's.

The second area of concern identified for those managing PD solo relates to disease management. From diagnosis through progression, the questions are endless. For those managing Parkinson's independently, the questions predominantly focus on support with decision-making to prepare for the advancing progression of Parkinson's.

Who will monitor my symptoms and side effects throughout the day, months, years? Who will participate in my medical appointments? Who will recognize and express concerns about potential cognitive issues I might not notice or compulsive behaviors resulting from medication? How long will I safely be able to stay in my own home? Who will coordinate my transition to care? Who will plan my funeral?

These questions can be stress or anxiety-inducing for anyone, but often even more so for those managing PD solo. There are things that can be done to mitigate these challenges and/or feelings of anxiety and stress. Although these challenges will have unique responses for each individual, there's a unified agreement that planning for eventualities in advance, building a strong support system and care team to lean on for support can be invaluable.

When thinking about daily disease management, there were many practical concerns expressed by the group, which were met with potential solutions. One of the concerns shared was fluctuating or decreasing energy levels throughout the day leading to difficulties with managing daily living tasks of nutrition through meal prep and cleaning. For nutrition, we discussed using meal services, such as Meals on Wheels or meal kit services (ex. Hello Fresh, Goodfood, etc), using an

air fryer for meals (this was highly recommended!) or trying to prepare meals during your best times of the day according to "on" periods with medications. For cleaning, we discussed cleaning manageable sections of your space when feeling "on" and motivated. We also discussed hiring a cleaning service for periodic deep cleans and personally maintaining with daily/weekly cleaning between.

The secondary practical concern shared was falls and getting up safely after a fall. The challenge with falls and solo PD is lack of direct support available after the fall and potential inability to call an emergency contact afterwards. We discussed the importance of fall detection devices (ex. Telus LivingWell Companion, Phillips Lifeline, etc) or purchasing a smartwatch (ex. Apple, Fitbit, Samsung, Garmin, etc) for a more discreet fall detection device. The final option that could be beneficial is a medical alert bracelet, available in the Aware in Care kit, to inform those in an emergency





situation about your diagnosis. Additionally, we discussed the importance of maintaining physical well-being through exercise and physiotherapy. For example, connecting to community resources such as specialty Parkinson's rehabilitation programs through AHS or community partners offering Parkinson's-friendly programs.

One of the big questions with Parkinson's, especially solo PD, is: how long will I be able to drive? Who will make the decision when it is unsafe to continue driving? How will I manage without a license? These are extremely important questions to consider, as driving is connected to our sense of independence and autonomy. Due to the uniqueness of Parkinson's, decisions about driving will be individual. The decision to retire your license can/will be made with careful self-consideration and input from your healthcare team. If you're feeling unsure about your driving, there are refresher "Brush-Up" courses available through Alberta Motor Association (AMA). If you have decided to retire your license, there are many alternatives available for transportation, including community resources (ex. Access-A-Ride Lethbridge, Access Calgary, Action Bus Red Deer, DATS Edmonton, Lloydminster Handi-Van, GPAT) or independent resources such as an electric bike.

The final area of concern when managing Parkinson's independently is finances. The group expressed concerns about a sole income leading to increased financial concerns and sole medication coverage leading to higher medical costs. We created a brief list, included below, of community and government resources available to support financial concerns:

- » Disability Tax Credit
- » Canada Pension Plan Disability (CPP-D)
- » Assured Income for the Severely Handicapped
- » Alberta Adult Health Benefit
- » Seniors Benefit for Dental, Health, and Optical
- » Alberta Aids to Daily Living

We understand that managing Parkinson disease independently is a challenging task with continual new concerns from progression. We want to emphasize the importance of planning, ahead when able, and reaching out to your support systems to help throughout your journey.

WELLNESS RETREAT

June 23-25 Canmore

Join us for this unique getaway experience featuring elements of personal wellness and physical activity.

Hosted by Calgary MDP Director, Dr. Davide Martino, this first of its kind retreat brings together opportunities for both those diagnosed and care partners, to learn, make friends and share in a variety of activities while enjoying the breathtaking sites and sounds of Alberta's majestic Rocky Mountains.

- **Activities for both People with Parkinson's and Care Partners**
- **Moderate to challenging mountain hikes & walks**
- **Yoga and mindfulness**
- **Art and music**
- **Wine & Cheese evening and Bonfire Social**



For more information or to reserve your spot
1-800-561-1911
parkinsonassociation.ca

\$500 per person*

Price includes:

- All planned activities
- Daily lunch and snacks

*accommodations not included

JOIN US FOR

Spring Socials

AND CELEBRATE

Parkinson Awareness Month

Please indicate which Spring Social you will be attending and if you plan to bring any guests.
Please call to register toll-free 1-800-561-1911

CALGARY REGION

April 5, 11 am-1 pm	Calgary North
April 6, 11 am-1 pm	Strathmore
April 13, 1:30-3 pm	Canmore & Cochrane
April 16, 11 am-1 pm	Calgary South
April 18, 11 am-1 pm	Airdrie
April 27, 10 am-12 pm	High River/Okotoks/Nanton

EDMONTON REGION

April 11, 10 am-12 pm	Sherwood Park
April 12, 1-3 pm	Camrose
April 18, 10 am-12 pm	St Albert
April 19, 1-3 pm	Edmonton
April 25, 1-3 pm	Fort Saskatchewan
April 25, 6:30-8:30pm	Leduc
April 27, 10am-12pm	Parkland (Spruce Grove, Stony Plain)

LETHBRIDGE/MEDICINE HAT REGION

April 19, 12- 2 pm	Medicine Hat
April 20, 2-4 pm	Lethbridge

GRANDE PRAIRIE

April 12, 1-3 pm	Grande Prairie
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RED DEER REGION

April 6, 2-4 pm	Rocky Mountain House
April 12, 1:30 -3:30 pm	Olds
April 19, 1-3 pm	Red Deer
April 26, 1-3 pm	Lacombe

LLOYDMINSTER REGION

April 4, 10:30 am-12:30 pm	Vermilion
April 18, 10:30 am-12:30 pm	Bonnyville
April 27, 12-4 pm	Lloydminster



NEW GROUP

SOLO PD SUPPORT GROUP

For those diagnosed with PD who do not have a spouse or Care Partner.
When: 2nd Thursday of the month, starts April 13.

Call **1-800-561-1911** to Register



April is

Parkinson Awareness Month

**JOIN US THIS APRIL AS WE
CELEBRATE OUR COMMUNITY**

We dedicate the month of April to raising awareness of those living with and affected by Parkinson disease and Parkinson's Plus Syndromes, the people that support and love them, and the needs of our community.

We are spending this April celebrating everyone in our community.
They empower each other!

Get involved this month:

Weekly Webinars: Wednesdays @ Noon

Week 1: Celebrating our Caregivers and Care Partners.

Week 2: The importance of educational and active PD programming

Week 3: Our Alberta-based PD research and research studies.

Week 4: Our Volunteer Community and their ongoing support

DONATE NOW

Go to www.parkinsonassociation.ca and donate today



EDMONTON

JUNE **11** 2023

CALGARY

JUNE **17** 2023

- Classic Car Show • Entertainment • Door Prizes •
- Complimentary Food and Beverages •

Get involved & join us at
www.parkinsonassociation.ca

