

Parkinson

# PULSE

Connecting people living with Parkinson disease in Alberta



*Home is Where  
the Heart is...*



Navigating  
Housing Transitions





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Spring 2021

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*Parkinson Association of Alberta is the voice of Albertans and their families living with Parkinson disease. Our purpose is to ease the burden through advocacy, education, client services and find a cure through research.*

We welcome your comments, suggestions and questions. Email us at [communications@parkinsonassociation.ca](mailto: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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**From the Desk of the CEO**

I have a tattoo on my left wrist that just says “home”. My husband and both our daughters have the same. When our youngest decided to venture afar for school, we realized our little home wouldn’t look the same as it had for the 18 years prior. That was a tough one for this mama bear! But our home wasn’t the house our family grew up in together. Rather, we were each other’s home. The four of us were our home. Thus, the tattoo; a reminder that our memories, our love and affection for each other, our future as a family, didn’t rely on a place.

This edition of Pulse talks about the practicalities of housing; when you know it’s time to move from one

place to the next and how to go about that. These are important discussions to have and much easier to plan for in advance than to be in a position where you have to react to unexpected or untimely circumstances. Beyond the practical though, are the emotional bonds we form around the physical home we have built for ourselves. Planning ahead gives you time for your heart to catch up with your logical mind. Transitions are a natural and important part of life and the team at Parkinson Association of Alberta is here to help talk through these decisions as you plan for your future.

April is Parkinson’s Awareness Month and we are so pleased to re-introduce you to our Circle of Help. Our goal at Parkinson Association of Alberta is to provide a safe and caring community of support so that when you or your loved one receive a diagnosis of Parkinson’s you know you are not alone. Throughout the month, we will be sharing online events and activities to continue to keep you motivated, active and informed. As our world has grown even smaller through technology and circumstances in the past year, we are excited to also share the work being done across the globe to spread awareness and advocate for meaningful investment and advancement in research.

March 16, 2021 marked one year since Parkinson Association of Alberta, like the rest of the world, changed the way we work. You – our clients, members, friends – have kept us focused and moving forward. We cannot begin to express our gratitude for your trust and ongoing support.

My sincere thanks,

Lana Tordoff,  
Chief Executive Officer

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The magazines we write and the themes we choose are a direct result of the conversations, feedback and inspiration the Client Services Team and I have received from YOU!! Let me give you a few examples.

The Summer 2019 issue **"Improving Communications"** came about when a client mentioned she was having trouble communicating with her spouse who was now in long term care and was having difficulties with speech. We brainstormed ideas and I realized I needed to go find more information.

The Spring 2019 issue **"On the Way Down...Swallowing and Oral Health Issues in Parkinson Disease"** came about after two different client conversations and/or challenges. One client wanted more information on drooling than I could give at the time. And the second client had a conversation with his Client Services Coordinator about "tips and tricks" noting that a bicycle handle grip he slid onto the end of his toothbrush had made brushing his teeth so much easier!! As a Team we were all so excited for such an innovative and real-world solution that we knew we had to share it!

The Summer 2020 issue **"Little Pieces... Finding Motivation in the Fight against Apathy"** came about after the entire Client Services Team discussed that many care partners had shared that they were struggling with this enigma of a symptom and its effect on their loved ones. We knew we needed to shed some more light on this important topic.

The challenges and success you share helps others. It is for you and because of you that we learn and grow as a staff and as a part of the Parkinson's community. The conversations you have with us, the insights you share

and the feedback you provide us helps create the path forward... together.

We would love to receive more feedback from you on our magazines – be it the issue as a whole or a specific article. Did something you read help you? Did you not care for a particular article? (It's ok, honest we want to know!) It is always our sincere hope that each issue will offer readers some level of insight or knowledge, AND start conversations be it at home or with peers! Below we share some feedback we received for our Fall 2020 issue **"In this Together... the Care Partner Issue"**.

Your feedback, comments, and insights are ALWAYS welcome! In fact, we would like to highlight them (as we've done here) in future magazines. Share your feedback with your Client Services Coordinator, **call us toll-free at 1-800-561-1911**, or **email us at [communications@parkinsonassociation.ca](mailto:communications@parkinsonassociation.ca)**.

*I just received the Fall edition of the Pulse Magazine and sat down and read it from cover to cover... something I would not typically do!*

***Thank you for focusing on Care Partners. As a past Care Partner the articles really touched me. Perhaps it was in part because I recently listened to CBC's Matt Galloway's interview with Lisa Raitt about being a Care Partner to her husband with early onset Alzheimer's. My late husband had Multiple Systems Atrophy and while we were fortunate to not ever encounter aggressive behaviour described by Ms Raitt there are many similarities to the information you highlighted in your articles. I think it is so important to acknowledge the role Care-Partners. I suspect when most of us made our marriage vows "in sickness and in health..." we thought it meant the sniffles. Little did we realize what it would entail. It isn't an easy role...and I am very grateful for the support of many, including Parkinson Association.***

*Nicely done.... and greatly appreciated!  
Laurel-Anne Millis*

# Home is Where the Heart is...

## Navigating Housing Transitions

Written By: **Brandi La Bonte**

Many of you are likely familiar with that iconic scene from the Wizard of Oz where Dorothy clicks the heels of her sparkly ruby shoes three times and says "There's no place like home." For many the scene and that line in particular is an anthem for anyone who is feeling homesick. For me, well, I always had a different take.

For me home has been 2 countries, 4 provinces/states, 13 cities and towns, and 28 different dwellings. And I consider every single one of those places to have been home at one point or another. So I guess what I'm trying to say is that I'm more of a "home is where the heart is" kinda person. Case in point, every time (and I mean every time) I go to Disneyland it feels like home to me even though I do not and cannot (believe me I asked) live there. And while I understand that not everyone feels this way; for me and many others home is more of a feeling than an actual, physical structure.

Over the course of our lives we go through so many transitions; and even though many of them are BIG changes (moving out of home for the first time, new job, having children, retirement, etc) many people welcome these transitions as positive changes. These transitions signify new chapters in our lives. However, as we age and/or Parkinson's progresses the changes may begin to have a negative connotation. Of course there are many who take it all in stride; but for some, transitions later in life, especially when it comes to housing, can cause feelings of stress and anxiety. And why wouldn't it? Deciding on where to live, when to move or if you should move is not only a practical choice... it's a very personal one. There is absolutely nothing wrong with having these feelings, they are natural. The good news is that while you may still have those fearful or negative feelings, there ARE things you can do to help alleviate them and plan for the best future for you and/or your loved one.

When it comes to housing transitions, there are many options available – from staying at home to downsizing to retirement communities and yes, even long-term care. Throughout this issue we spend some time going

over all of your options to provide you with information and insight regarding the choices available to you.

The very best piece of advice I can give you based not only on research but also first-hand accounts from clients (both people with Parkinson's and Care Partners) themselves is to start having these conversations early! I know, like many difficult conversations about health, life, and death, it can seem daunting and uncomfortable. Clients have told us they put off talking about difficult topics because they didn't want to "jinx it", they didn't want to "hurt my loved one's feelings", or they thought they "had more time."

So let's, for a moment, go back to that earlier paragraph about big changes and transitions – what contributed to them signifying positive, new chapters? The answer, in most cases, is choice. The ability to choose is a powerful feeling. It gives us a sense of purpose, control and independence. Life (and Parkinson's) however can diminish, alter or remove some of those feelings – so we can, and should, make the choices that are best for us when and while we can. And, because life changes, so too can (and will) your plans. This is ok! You aren't going to jinx anything. Talking about future housing options can be empowering. And, time... well, what does that even really mean?

We save time. We waste time. Time is of the essence. Time is money. We are robbed of time. We lose time. We have all the time in the world... until we don't.

Home is where your heart is; and we encourage you to read through this issue with that sentiment in mind. Navigating housing transitions and all of the options available to you may seem overwhelming; but remember the Client Services Team is here to help!

And finally, speaking of transitions and the CS Team, I am excited to share with you that this magazine features articles written by members of the **Client Services Team!!** Don't get me wrong, I certainly enjoy writing articles for you (and will continue to do so), but I am beyond thrilled for everyone to see just how incredibly knowledgeable, talented and compassionate this Team is!



## Aging in Place

Written By: **Brienne Leclaire**

**"I want to stay  
in my own home."**

As we get older, or as Parkinson's progresses, this sentiment is likely something you and/or your loved one has considered. The good news is that with the right help you might be able to do just that. Choosing to stay at home, also called "aging in place", can come with worries and concerns about ensuring your health and safety needs are met. In this article, I've outlined some things to consider to help you determine if aging in place is the right choice for you and/or your loved one, and how to do so safely.

Safety is the number one priority when making the decision to age in place. It is important to take some time to really think about the day-to-day activities that are a part of life at home. Activities including (but not limited to) personal hygiene, cooking/eating, taking medication, mobility in and outside the home, and cleaning/home maintenance need to be done both effectively and safely. It is important to be honest with yourself and/or your loved one when determining if these activities can be completed in a realistic manner. It is also important to note that if there ARE specific daily activities you are unable to do safely or effectively; it does not mean aging in place is not possible.

After identifying daily activities that cannot be met currently or in the near future, it is time to look at what can be done at home to accomplish these daily tasks. This can mean modifying your home or the activity itself; or bringing in extra support for that activity. In the next section we will discuss some daily activities and layout some possible ways to help meet these daily tasks. This list is not extensive there may be other activities or other ways to help meet these needs that are unique to the area or individual. These are some ideas to get you started and thinking about aging in place.

### Personal Hygiene

Personal hygiene activities can include (but are not limited to) bathing, dressing, personal grooming, dental hygiene, and toileting. Home modifications can be beneficial in helping in these tasks. Equipment like grab bars, rails and bath/shower chairs can help make these tasks easier and safer to complete. Getting such



equipment can be done at medical supply stores or through home care. If these types of adaptive tools are not enough, Home Care can help with a broad range of daily activities to help with aging in place such as dressing, grooming, bathing and other personal or medical needs.

### Cooking and Eating

If preparing food is a task where you are experiencing challenges; there are supports that might be able to help. Consider having family or friends help you make meals in advance that can be frozen or refrigerated for the week or month ahead. Meal delivery programs are also a good option. These are often hosted out of senior's centers or community organizations, though availability varies by region. This service typically delivers at least one hot meal per day for a small cost. Another option is pre-paid meal kits or subscriptions





where ingredients and recipes are delivered to you to make your own meals. These vary in cost and can be pricy depending on company and dietary needs. Another option is ready made meals found in grocery stores that only need to be heated. Be mindful of high sodium, you can find this information on the package's nutrition panel.

If eating is one of the more challenging tasks; adaptive tools are also available for this. There are many options depending on the challenges encountered while eating. Some examples are weighted or large grip utensils and plates or bowls with special ridges to help get food onto the utensil.

## Medication

Taking your medication at proper intervals and dosage is important for your health. Many pharmacies offer blister packs so that medication is already prepackaged into the dosage and times its to be taken. This system may need to be slightly modified depending on intervals for Parkinson's medication as many blister packs have a limited amount of time slots. Most box stores and pharmacies carry refillable plastic pill packs that can be customized to fit your medication needs. Setting alarms can also serve as a reminder for taking medication. Home care can also help with administering medications and other health or medical needs.

## Mobility

In the context of aging in place mobility means both the ability to move from one place to another to complete tasks; and one's ability to move around within the community to complete tasks. When it comes to mobility within the home, downsizing the area used within the home is something to consider. This can mean adapting your use of space to living on one vs two levels or reducing the number of stairs and area used to meet daily needs. There are many different mobility aids available that can be used inside and outside the home; examples include walkers, canes, and wheelchairs. These items can make completion of daily activities easier and safer.

If you are unable to drive that can present challenges when it comes to completing activities outside the house. For example, picking up prescriptions, groceries or attending doctors' appointments. To tackle this challenge there are two major resources outside of family and friends that can be utilized. First is ride services like taxis, volunteer drivers, and public transportation. Many seniors' centers or volunteer organizations run free or low-cost ride services, so this can be a good place to start. We can help you find out what ride services are available in your area. The second resource is delivery services. Many pharmacies, grocery stores and retail stores offer delivery. This varies in

cost and availability by location. Check with stores and pharmacies to see if they offer delivery services.

## Cleaning and Home Maintenance

These activities can be difficult depending on your individual limitations. It can feel overwhelming to maintain a home and/or yard. If downsizing your dwelling isn't an option, there are a few things that can be done to help you. Having supplies that are lightweight and easy to use can help reduce challenges in cleaning and maintenance. This can be things like light weight vacuums, equipment on wheels or items modified to fit mobility needs. There are also many private and volunteer resources that can be hired or engaged to help with cleaning and maintenance. These vary in cost and availability but a good place to start looking is your local seniors' center. If looking to hire ongoing help with cleaning or outdoor maintenance, services are available at a range of prices depending on area.

Choosing to age in place can come with its own challenges and transitions. It is important to make sure you and/or your loved ones are safe, and needs are met. Ask for help and explore the options available in your area. Friends, family, and, of course, Parkinson Association of Alberta, might be able to help you with some of these tasks or help in setting up supports you might need.

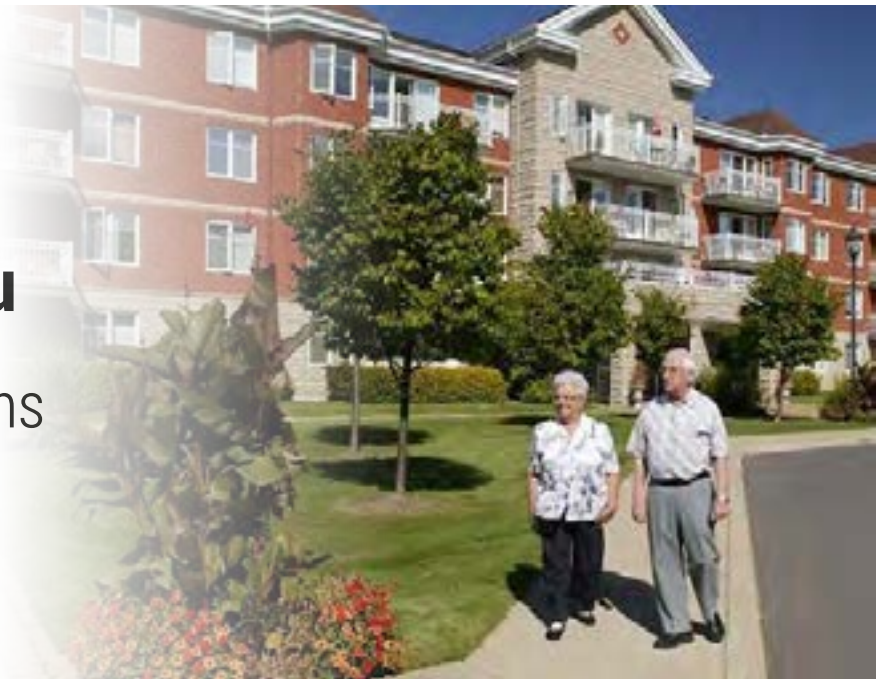




## A Place that is Right for You

### Seniors Housing Options

Written By: **Declan Beddow**



As Parkinson's progresses many people begin to seriously consider their housing needs, and whether or not their current home is meeting those needs. You may struggle to get up and down the stairs in your current home, or maybe you live in rural or northern Alberta and would like to be closer to medical services and accessible transportation, or perhaps you would just like to live closer to your family.

Whatever your reasons for moving are it is important to know what all your options are and the services and care each option provides. This article will outline the most common housing options, both independent and supportive living (also called assisted living), which you may want to consider when your home is no longer meeting your needs.

#### Independent Living/Seniors Apartments

Independent living or senior's apartments are ideal if you are looking to downsize but are still able to perform all of your day-to-day tasks. Often, people with Parkinson's will consider moving into one of these apartments because of the upkeep that is required when you own a home, or to eliminate the need to climb stairs by having everything on one level. Depending on your income you may be eligible to receive a fixed rate for your rent equal to 30% of your pre-tax income, which can be extremely beneficial for low-income seniors!

#### Seniors Lodge

A senior's lodge is a type of communal living where each individual or couple gets their own room (usually a bachelor suite without a kitchen) but, meals, cleaning and laundry is provided for you. There is also some amount of communal space for eating meals or participating in activities and entertainment provided

by the lodge. This is a good option if you are still fairly independent and able to complete most day-to-day tasks but would prefer to not have to worry about cooking or cleaning. Living in a lodge does not mean giving up your independence! You can come and go as you please, like you would any other apartment. Monthly prices vary from place to place so it is a good idea to compare the prices and amenities of lodges in your area if you think this style of home is right for you.

#### Supportive Living

Seniors' apartments and seniors' lodges are great options for individuals who are fairly independent but what about options for individuals who require a higher level of care? In this section we will discuss how to access supportive living and long-term care facilities in Alberta, the monthly cost, and the level of care provided.

The first step to accessing a supportive living facility is to contact a Home Care Case Manager and request a supportive living/long-term care assessment. If you haven't accessed home care before you can call 8-1-1 in Alberta and request to be connected with a case manager in your area. Once you have been assessed and it is determined that you would be appropriate for assisted living you will be placed on a waitlist for facilities in your area.

So, what is the difference between a supportive living and a long-term facility? Well, both services cover rent, meals, housekeeping, linen and towels change, building amenities and recreation programming. The main difference is in the level of care required and the staff of the facility. Supportive livings are staffed by health care aids who can provide support, personal



care, and medication assistance. Individuals who reside in supportive living must be medically and physically stable, able to move by themselves or with the assistance of one other person, use a call system, and not be a risk to themselves or others.

A long-term care is staffed by a nurse who will oversee care, licensed nurse practitioners, and health care aides. People who have highly complex and unpredictable health needs whose care cannot be safely provided in their own home or in supportive living would be appropriate for a long-term care.

The cost of living in a supportive living or long-term care can vary depending on a few factors, for simplicity we will briefly touch on private facilities but focus our discussion a little bit more on the public facilities.

Private facilities are always an option for people looking to live in a supportive living environment, but the cost can vary significantly from publicly funded facilities.

The cost to live in a publicly funded facility is between \$1,743 and \$2,120 per month based on the type of room, and whether it is shared with another resident or not.

The Government of Alberta offers additional financial assistance to seniors who make \$28,785 or less per year, and senior couples with a combined annual income of \$46,745 or less. This is offered through the **Supplementary Accommodation Benefit**. This is a financial program designed to help low-income seniors who reside in a supportive living or a long-term care facility. This is a sliding scale program with a maximum yearly benefit of \$11,771 for individuals and \$15,202 for couples. The closer your income is to the maximum the less money you will receive.

I hope this article has given you an idea of the housing options which are available seniors in Alberta. Some areas have been simplified for brevity, but if you have further questions, please contact your Client Services Coordinator.





## Important Dates to Remember



World Parkinson's Day is **April 11**

All PAA Offices will be closed on **May 24 (Victoria Day)**

All PAA Offices will be closed on **May 27 & 28** for our annual all staff meeting. Online programs will run as scheduled.

Parkinson Association of Alberta's Annual General Meeting (AGM) will be held on **May 29**

**PUT THIS ON YOUR CALENDAR!**



## COVID-19/Pandemic Update

At press time COVID-19/pandemic restrictions are not conducive for our indoor and in-person program offerings. While we wait for more shots in arms and warmer days we will continue to offer a variety of support, education and active programming options by online and telephone delivery.

- 43 Support Groups
- One-on-One/Family Support
- Free exercise on Mondays & singing on Fridays
- 2 free education presentations a month
- Free ZOOM and YouTube tutorials
- A variety of paid active programs such as exercise, voice, and cognition options

Contact a Client Services Coordinator or call us toll-free at **1-800-561-1911** to get all the latest information on programming.

## Magazine Changes

In order to align with projects behind the scenes and better showcase our events like Step 'n Stride, we have made the decision to re-schedule our magazine.

**Moving forward the timeframe will be as follows:**

**Spring 2021 – Now**  
**Summer 2021 – will be out in July**  
**Fall 2021 – will be out in October**  
**Winter 2022 – will be out in January**



**We are excited to announce that we are launching a NEW program this May!**

We've partnered with AHS and the University of Alberta's Rehabilitation Medicine Department to pilot a new **Speech Program designed specifically for people with Parkinson's!**

This program will be offered virtually (online) which is so exciting as people from across Alberta will be able to participate!! It's never been easier to keep your speech clear and your voice strong!!

More details will be available soon, but we wanted to let you know that you can call or email us now to add your name to the "I'm interested list" in advance as **space will be limited.**

Give us a call tollfree at **1-800-561-1911**, emails us at **info@parkinsonassociation.ca** or contact a Client Services Coordinator today.

# EVENTS

**4x4x48  
Challenge**

4 miles every  
4 hours for  
48 hours



## CENTURY 21. Foothills Real Estate

### Century 21 Foothills

Century 21 Foothills has been a friend of PAA for three years! We are truly grateful for their past support of our events, including the Diamond Evening event in High River and our annual Flexxaire Parkinson Step 'n Stride. And they have chosen us to be their charity of choice for April! Thanks to their support, you might hear radio ads on AM 1140, Sun Country and The Eagle. Our organization and the Parkinson's Community are stronger because of partners like Century 21 Foothills.

### Jacqueline McKay's Fundraiser



Jacqueline McKay has lived in Brisbane, Australia for a year now. Her father, Bill was diagnosed with Parkinson's 7 years ago, which motivated her to fundraise for Parkinson's research in Alberta this past March. Jacqueline was inspired by the **David Goggins 4x4x48 Challenge**. She completed this challenge on Sunday, March 7 as her family, friends, and PAA staff joined her on Zoom. Some ran or walked with her, while others cheered her on. She told us that "some have called me crazy to partake in this intense challenge, but those suffering from Parkinson's have truly inspired me." In two weeks, Jacqueline raised over \$2,900 for research! We can't thank her enough for her passion and efforts – not all of us have the drive to accept such a challenge!



The activities of Parkinson Association of Alberta are monitored by our passionate volunteer board of directors that meets bi-monthly. The board makes and amends policy decisions about our organization, its resources and activities, and communicates its vision to members and the public.

As a current member\* of PAA, we welcome you to our **2021 Annual General Meeting on Saturday, May 29 at 11:00 AM** in Edmonton (PAA Edmonton Office – 11209 86 ST NW). Participation will be available virtually. With consideration of changing restrictions on in person activities in Alberta, it is

anticipated that only a small number of guests will be able to attend in person. Please RSVP and we will advise as we near closer to the event as well as share the ZOOM link. **RSVP to [ngaudet@parkinsonassociation.ca](mailto:ngaudet@parkinsonassociation.ca) or by calling 1-800-561-1911.**

**\*Any member in good standing shall have the right to one vote providing he or she has been a member in good standing for at least 30 days prior. To be considered a current member, memberships must be purchased or renewed no later than 4PM on Friday, April 29, 2021. Memberships can be purchased on our website or by calling our office.**



## Making a Move

### Downsizing Your Dwelling

Written By: **Emma Torneiro**

Downsizing defines the process of minimizing in preparation to move into a smaller residence. The idea of downsizing is common for aging individuals due to multiple factors (many of which my teammates have covered throughout this issue). The process generally includes a mixture of downsizing personal items (ie: furniture, clothes, mementos, etc) and reducing total square footage of the home. Downsizing, just like your Parkinson's, is completely unique to you and your situation. I happen to know a Calgary realtor, Rui Torneiro, and reached out for an interview to answer common questions about downsizing to help you start the process!

**Emma Torneiro (ET):** What are the common options available for downsizing?

**Rui Torneiro (RT):** In terms of dwellings, you can downsize the total square footage and size of your home or move into another type of home. The other options types include apartment, townhouse or villa, bungalow, duplex or bi-level spilt. When you or your loved one require more assistance and care, the options may include residing with family, assisted living facilities or long-term care facilities. A realtor would be able to support you through the transition by selling your current residence and assist in the process of finding and buying a new residence.

**ET:** What are the benefits of downsizing?

**RT:** There are many benefits to downsizing, especially as individuals age and their health changes. In my opinion, these are the benefits to downsizing:

- Minimizing or simplifying lifestyle to suit current needs
- Less maintenance and cleaning required in smaller homes
- Financial costs decrease, including mortgage payment, utilities and overall expenses

- Level of stress can decrease when moving into smaller or more manageable home
- In homes with minimal or no stairs, the risk of falls decreases
- The total carbon footprint decreases for smaller homes
- For condo buildings, there is more sense of community from other tenants and increased sense of security when leaving building for extended periods of time, such as vacations
- Your financial standing may improve from selling property and purchasing smaller or less expensive property
- You are able to create new beginnings in a new home! The most important aspect of this benefit is the ability to control the changes in your life before it become necessary.

**ET:** What influences an individual's decision to downsize?

**RT:** The primary factors that may influence the decision are:

- Health and health care needs
- Age
- Lifestyle changes
- Mobility
- Finances
- Proximity to resources and family members
- Accessibility
- Driving

**ET:** What initial steps would you recommend people take before contacting a realtor to downsize?

**RT:** The first step towards downsizing is minimizing personal effects, which can be extremely difficult but will decrease the number of items that need to be packed and moved. Without really realizing it, we accumulate an excessive number of personal items



throughout our lives. Unfortunately, when downsizing it is next to impossible to bring every item to your new home; so it is important to determine which items are essential before moving.

The second step would be determining your financial position for buying a new home and/or selling a current home. If you currently have a mortgage, it is recommended that you contact your mortgage broker to determine penalties for ceasing mortgage early, ability to transfer mortgage to new dwelling or pay any additional outstanding fees. Be aware of the costs associated with the process of buying or selling. The list of costs includes realtor fees, legal fees, real property report (RPR) fees, insurance, and condo documents. As a proactive step, you can determine which documents need to be procured prior to sale of property and begin arranging documents.

The final steps before contacting a realtor would include determining which type of home is required, which area(s) you would prefer to live in and create a list of "must haves" for the home. Once you have finalized these steps, you are ready to contact a realtor and begin the search!

**ET:** If you are downsizing due to health and/or mobility, what should you look for in a home?

**RT:** When downsizing due to changes in health or mobility, it is important to inform your realtor of your accommodation requirements to work together towards finding the right property for yourself or for you and your loved one.

The first aspect I would recommend considering is a home with minimal or no stairs at the exterior entrances and within the home to ease mobility throughout. I would personally recommend houses with primary living on main floor, such as a bungalow or apartment/condo with elevator. The second factor to consider is the accessibility within the home, specifically in

the bathrooms. It is important to test the space in the bathroom to ensure there's enough room for a wheelchair or walker and enough room to easily move around. If you or your loved one requires support with personal hygiene, the bathroom must be able to accommodate two or more individuals. I would recommend measuring the total space of the bathroom and the width of the doors or entry ways, compared to width of mobility aids. Additionally, the flow and layout of the house must accommodate your specific needs. It is recommended to purchase a dwelling that can accommodate both current and future living requirements. If possible, I would recommend assessing the bathroom and general living spaces to determine if mobility aids, such as grab bars, can be installed in the future.

The other aspects to assess in current or future homes is sufficient storage and level of maintenance the house would require. As mobility or health conditions change, the ease of maintaining a house may decrease. It is recommended to purchase a home that is relatively low maintenance or consider options where maintenance is covered, such as condominiums or assisted living facilities.

The main advice I would recommend is consider your abilities and mobility needs before beginning the search for a new home. Once you have assessed personal mobility needs, the search for homes can be narrowed and your realtor is better suited to work with you to find the perfect home.

At Parkinson Association of Alberta we understand how the process of downsizing and/or moving can be a daunting, challenging or difficult transition, but we are here to help you!





## Difficult Decisions

### The Long-Term Care Conversation

Written By: **Ashley Ploof**

Choosing to transition a loved one into a care facility can be a difficult decision. Making this decision can come with different types of complex feelings. I've spoken to a few Care Partners who have felt relieved but also guilty and others who have been heartbroken. It is important to know that whatever you might be feeling is okay. Everyone makes the decision of how to provide the best care for a loved differently and with this, comes different emotions.

Many Care Partners who have travelled this path say it's best to have this conversation early. It can be a difficult conversation for sure, but it can also make the journey a little easier when it is time. Also, having these conversations early can help your loved one be an active participant in the decision making. From discussing what options are available, to doing research on and looking at different facilities can help maintain independence in decision making. If you need help initiating these conversations, there are many professionals who can help, including but not limited to your Client Services Coordinator, a pastor or a social worker.

In these conversations of how you will care for your loved one, try not to make promises about how you will care for them. It might be tempting to make a promise like you "would never put your loved one into a home". It makes sense that these words are comforting in the moment, but there is no way to know what challenges the future may bring and what decision might be best. I have spoken to many Care Partners who say it is good to remember that even the best laid plans might have to change.

It can be hard to adjust after your loved one moves into a care facility. It might take some time to for you to get used to a new routine of living alone and visiting your loved one. There may even be feelings of loneliness or loss as you transition to this new normal. A Care Partner I spoke to recently shared that the hardest part of this change was their loved one feeling abandoned in their new home. Their number one tip was to provide reassurance to your loved one. You can do this when you visit, and others can help remind them that you are still there for them.

Speaking of others; including others in these conversations (not necessarily the decision itself) such as adult children or siblings can be beneficial.



Sometimes people who love you can have strong opinions of what they think is best. It's helpful for them to hear what both you and your loved one want in the future. If it's not possible or beneficial to include them in the conversation, try to keep them informed. Letting family and friends know what you both want helps everyone adjust when it is time for the transition.

Whether you are struggling to accept the changes or you're just feeling a little bit sad, the following tips might help.

#### **If you feel guilty, try to forgive yourself**

Nothing you did caused your loved one to need to move into a care facility. Recognize that you are human and are doing the best you can; your best is more than good enough. Sometimes people need more care than we can handle ourselves.

#### **Take care of YOU**

Your loved one is in a safe place and receiving the care and support they need. Though it may be difficult at first, you now have some time to take care of your physical, emotional, spiritual and social needs, which you may have overlooked in the past. Set a schedule for visiting your loved one and remember that it doesn't have to be every day. There are many new activities to keep your loved one busy and help them adjust to their new home, as you both adjust to your new normal.

#### **Stay social and get support from others**

Spend time talking to friends, family, or other Care Partners. It's possible that you might feel lonely at first. Find people to walk through this journey with you and lean on them when you need to. This is a change for you, and it is not only okay, but healthy to ask others for support.

This transition can take time to get used to. It is okay to feel or not feel certain emotions. Focus on your needs and take extra time to care for yourself. Try to remember that you made this decision because it was the best thing you could do for you and your loved one.





# Planning for Long-Term Care

Written By: *Sherry Bower-Gagne*

Change is hard! And transition is just a fancy word for change. Of course, change and transitions aren't always hard, especially when made by choice; but what about those times when the transition is less within your control? Like aging? Or like Parkinson disease where transition can happen a number of times? At some point in our lives the time will come to start making plans or choices regarding the best living arrangements for yourself or your loved one. This, I know, can leave you with a LOT of questions. Where do I/we start? What are my/our options? How do I/we plan the transition? How do I/we choose the best place for myself or my loved one? It can all seem overwhelming on top of having to deal with an often, emotional decision. The good news is we can help get you started and provide insight and guidance every step of the way! From helping you explore your options, to compiling a list of facilities close to you, to dealing with the emotional aspects of this transition overall – we are here to help!

While it is true, not everyone transitions into long-term care (Home Care, live-in help, or supportive living may be better options for you) in this article I'm focussing on this particular transition. So, where to begin... well, we all know what they say about ducks in rows...

Having one's "ducks in a row" is simply a fancy (and fun) way of saying "having a plan". Choosing a long-term care facility is not like picking up some milk at the store. I've had discussions with clients across the province who've said it felt overwhelming and stressful or that there were "more things to consider" than they had originally anticipated. Many also said they felt unprepared because they hadn't had conversations or made plans in advance. So, before we go any further I would like to make an important point – the BEST time to have the conversation about transitioning into or planning for long-term care is BEFORE you or your loved one need to actually make that transition.

Alright, back to the planning. A great place to begin is by making a list of things that are important to you and/or your loved one. This could be things like location, cost, a private or a shared room, etc. This list is personal and will help you narrow down your search.

The next step is gathering a list of facilities (we can help!) that meet your original criteria. Depending on where you live in the province and/or availability you



may need to adjust your criteria to better match what is available near you. Much like house hunting, finding the place that is right for you and/or your loved one takes time. This will be your (or your loved one's) new home and you will want to make sure that the place you choose has as many of your/their personal wants as possible. Taking the time to plan, research and scouting ahead can be a good way of making sure that you don't face the pressure of having to take the first available space. It will ensure that the fit is right for you and/or your loved one and give you peace of mind.

After you have your list of locations it's time to narrow things down further by visiting the facilities. We've provided a list of topics, questions you may want to ask staff and things to consider on the next page. They won't all apply but will hopefully help you in your search.

Be sure to visit the facility more than once, visit at different times of the day so that you may get a good overview and a sense of how you feel visiting there. When visiting take notes so that you can review them later, document any concerns so that you can ask about them and have them to refer to them later.

While we, of course, cannot make any decisions for you; as your Client Services Coordinators we are happy to speak with you as often as you need to ensure that you have looked at all the pros and cons along with talking through any of your concerns. The most important thing is that you feel comfortable with your decision and have peace of mind.

## Physical Facility

How many residents live in the facility? How many floors are there? How many elevators are there? Is the facility bright and pleasant? Does it look and smell clean? Is the furniture in good repair? Are there private areas for residents and visitors? Is there an outdoor area?

## Resident Rooms

Are rooms private or shared? Can married couples be housed together? Are resident rooms bright and home-like with personal belongings evident? Do they allow for patient privacy? Can residents have their own phones, TV, or computer in their room? Are the bathrooms clean, safe and is there enough towels? Do staff knock before entering?

## Staff

What is the staff to resident ratio? How do they cope with staff shortages? Do staff appear well trained? Do they treat residents, family and other staff with respect, dignity and courtesy? Are they patient? Do they treat the residents as adults? Are staff trained to work with visually or hearing impaired residents?

## Medical Access

Can one continue receiving care from a family doctor after admission to the facility? Is a physician on call 24 hours a day? Is a Registered Nurse on duty 24 hours a day? Is the staff physician a geriatrician? Is the staff physician or doctor on call willing to spend time talking to family members regarding medical care of the resident? Are the physicians and/or medical director available to take calls from families? What is the facility's policy on cardiopulmonary resuscitation? – It is not necessary to sign a DNR (Do Not Resuscitate) form on admission.

## Parkinson disease – specific

Ask about their understanding of Parkinson disease and how flexible their medication regime is.

## Access to Allied Health Care

Are physiotherapy, speech therapy, and occupational therapy training available? Are dentists and dental hygienists available to provide dental care? Are social work services available at the residents' request? Who arranges for these support services?

## Care Plans/Day-to-Day Care

Inquire about residents' assessments and care plans. How often do case conferences occur? Are residents and representatives (substitute decision makers) involved in the case conferences and planning for the resident's care? Are the assessment information and care plans

available to residents and family (or substitute decision makers)? How often are the care plan review meetings?

## Dining

Do dietary staff respect individual eating habits? Are there menus on display? Do staff oversee residents as they eat (help with feeding, ensure food is bite-sized, etc)? Do the meals look appetizing? Are family members welcome to join the residents at meal time?

## Activities

Are there appropriate activities? Are activities posted? Are there exercise and vocal programs? Is there a library or visiting library service? Are the residents lined up in wheelchairs in hallways? Are they involved in activities?

## Safety (Facility and Resident)

Does the facility have a sprinkler system? If not, what are the plans for installing one? Are there regular fire drills for all staff (including part-time)? Does the local fire inspector make regular visits? What is the facility's policy on restraints and medication? Is there a specialized unit for persons suffering from dementia or serious behavior problems? Do staff have training in managing difficult/aggressive behavior?

## Cultural questions

If English is not the resident's first language, will an interpreter be available when necessary? Are there culturally appropriate foods available? If applicable, are there programs and services available to meet the diverse cultural needs of the residents?

## Visiting

Is there free or limited access to the facility? Are there specific times when visitors are not allowed? Are people encouraged to visit? Are residents' religious representatives encouraged to visit? Is there a volunteer program in the facility?

## Application & Fees

What is the application procedure? What are the accommodation fees/fee co-payments? What services are included in the fees (ie: personal supplies and/or grooming, laundry, etc)? What services is the resident/family responsible? Are additional services available? If so, what are they and how much do they cost? How and when are residents/families notified of a change in fees/service?

**REMINDER:** Advance REGSITRATION is REQUIRED for each and every Support Group. Support groups may not run if no or minimal registrations have been received.

**Please note that Support Groups will not run on statutory holidays.**

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

<b>EDMONTON REGION...continued</b>	<b>780-425-6400</b>
<b>WESTLOCK</b>	
3rd Thursday ( <b>new day &amp; time</b> )	10:00AM
<b>WHITECOURT</b>	
3rd Thursday ( <b>new day &amp; time</b> )	10:00AM
<b>GRANDE PRAIRIE REGION</b>	<b>780-882-6640</b>
<b>GRANDE PRAIRIE</b>	
2nd Wednesday	2:00PM
4th Wednesday – <b>Care Partners</b>	11:00AM
<b>LETHBRIDGE &amp; MEDICINE HAT REGION</b>	<b>403-317-7710 403-526-5521</b>
<b>LETHBRIDGE</b>	
3rd Thursday	2:00PM
<b>MEDICINE HAT</b>	
4th Thursday	1:30PM
<b>SOUTHERN ALBERTA (ZOOM/CALL-IN)</b>	
2nd Thursday	2:00PM
<b>LLOYDMINSTER REGION</b>	<b>780-808-5006</b>
<b>BONNYVILLE</b>	
3rd Tuesday	10:30AM
<b>LLOYDMINSTER</b>	
2nd Monday – <b>Care Partners</b>	10:00AM
4th Tuesday	2:00PM
<b>VERMILION</b>	
2nd Tuesday	1:00PM
<b>RED DEER REGION</b>	<b>403-346-4463</b>
<b>CARE PARTNER (ZOOM/CALL-IN)</b>	
3rd Thursday	2:00PM
<b>CASTOR</b>	
4th Tuesday (Feb, May, Aug & Nov)	1:30PM
<b>LACOMBE</b>	
4th Wednesday	10:00AM
<b>OLDS</b>	
2nd Wednesday	1:30PM
<b>RED DEER</b>	
3rd Wednesday	10:00AM
<b>ROCKY MOUNTAIN HOUSE</b>	
2nd Thursday (Jan, Mar, May, Sep & Nov)	2:00PM
<b>THREE HILLS</b>	
3rd Thursday ( <b>new day &amp; time</b> )	10:00AM





# CIRCLE OF HELP

Presented by Bayshore Home Health

## Creating a Circle of Awareness, Support, and Hope

Written By & Graphics By: **Alicia Jeffrey**

A Parkinson's diagnosis can be intimidating and confusing, but this Parkinson's Awareness Month, we want to show Albertans impacted by Parkinson disease and Parkinson's Plus Syndromes that they are not alone. We are here to help. Through our support, active and educational programs, we offer tools to better understand the road ahead as part of a safe and welcoming community.

### Our family invites yours to connect and share in the Circle of Help.

Our programs and research initiatives are made possible through the generosity of our community. Donations and the purchase of annual memberships allow us to create a welcoming and supportive space for Albertans with Parkinson disease and their families and friends.

We thank Bayshore Home Health for supporting our ability to develop educational content to be shared with you throughout the month of April and beyond.



## JOIN OUR CIRCLE OF HELP



### GIVE A GIFT

Text **HOPE** to 80100 to donate \$10 or \$25 to Parkinson Association of Alberta



### SHARE ON SOCIAL MEDIA

Tag us and use the #circleofhelp



### BECOME A MEMBER

Join our safe and caring community of support.



## Carol & Keith

"Nearly a year ago we got the diagnosis that my wife Carol has Parkinson's disease. This was really disheartening as we had lost my older brother Don just two years earlier after a long stretch of years fighting this dreaded disease."



## Mary & Norm

"Like most couples, getting a Parkinson's diagnosis was overwhelming to us. We didn't know much about the disease and had no idea what to expect in the future. We visited the Parkinson Association of Alberta office, where we were provided with information, resources and assured we weren't alone. What a relief!"



## The McKay Story:

"This is an ambitious and intense challenge, but those suffering from Parkinson's have truly inspired me."

# Provincial Support Groups

Written By: *The Client Services Team*



Support groups are a great way to connect with peers and gain valuable insights and information. While many of our readers may be aware of the “traditional” general support groups we facilitate across the province, you may not be aware of some of the more specific groups we now offer.

Each group was developed in response to client feedback based on their unique experiences. These provincial groups are facilitated by our trained staff and are accessible via ZOOM and telephone call-in. Registration information is located on page 17.

## DBS/Duodopa Support Group

**When:** 1st Tuesday of every month at 1:00PM

**Who is this group for:** Individuals diagnosed with Parkinson disease who have had Deep Brain Stimulation or the Duodopa procedure, their care partners and family members.

- Connect with and receive peer support from others who have undergone these surgical interventions. Share experiences, information, and tips and tricks, as well as learn from others’ experiences with these devices.

## Widow/Widowers Support Group

**When:** 1st Thursday of every month at 9:30AM

**Who is this group for:** Widows and widowers of a loved one who had Parkinson disease or a Parkinson’s Plus Syndrome (PSP, MSA, CBD, and LBD)

- Connect with and receive peer support from others who have lost a spouse. While supporting one another, this group will provide a safe space approach the sometimes difficult topics of grief, loss, and what comes next.

## Under 55 Support Group

**When:** 2nd Wednesday of every month at 7:00PM

**Who is this group for:** Individuals who are currently age 55 or under who have been diagnosed with Parkinson disease or a Parkinson’s Plus Syndrome (PSP, MSA, CBD, and LBD) and their care partners.

- Connect with and receive peer support from others who are dealing with Parkinson disease at a younger age. This group will focus on specific challenges faced by individuals in this stage of life such as talking to children about PD, employment concerns, and navigating a social life.

## General Parkinson’s Support Group

**When:** 3rd Thursday of every month at 10:00AM

**Who is this group for:** Individuals diagnosed with Parkinson disease, their care partners and family members.

- Maybe you don’t have a Parkinson’s Support Group near you; or maybe you want to attend a group more than once a month or on a different day than one closer to you... This group is for you!! Share experiences, information, and tips and tricks, as well as learn from others’ experiences with Parkinson’s.

## Parkinson’s Plus Support Group

**When:** 3rd Saturday of every month at 12:00PM

**Who is this group for:** Individuals diagnosed with a Parkinson’s Plus Syndrome (PSP, MSA, CBD, and LBD), their care partners and family members.

- Connect with and receive peer support from others who are living with a Parkinson’s Plus diagnosis. This group will focus on the unique challenges associated with Parkinson Plus Syndromes and include education, resources and shared experiences, tips and tricks.

# 'Tis Home Where'er the Heart is



'Tis home where'er the heart is  
Where'er its loved ones dwell,  
In cities or in cottages,  
Thronged haunts or mossy dell.

The heart's a rover ever,  
And thus on wave and wild,  
The maiden with her lover walks,  
The mother with her child.

'Tis bright where'er the heart is,  
Its fairy spells can bring  
Fresh fountains to the wilderness,  
And to the desert – spring.

There are green isles in each ocean,  
O'er which affection glides;  
And a haven on each shoreline,  
When Love's the star that guides.

'Tis free where'er the heart is;  
No chains nor dungeon dim,  
May check the mind's aspirings,  
The spirit's pealing hymn!

The heart gives life its beauty,  
Its glory and its power, --  
Its sunlight to its rippling stream,  
And soft dew to its flower.

Taken from *"The Winter's Wreath"* (1823-1857)

Published on October 20, 1828,

The Morning Post, London, UK

APRIL IS

# PARKINSON'S AWARENESS MONTH



PDAssocAB



ParkinsonAssociationofAlberta



ParkinsonAssociationofAlberta



**CALGARY, EDMONTON, RED DEER & LETHBRIDGE**

SUNDAY, APRIL 11