

Parkinson PULSE

Connecting people living with Parkinson disease in Alberta



The Power of CHOICE

Advanced Care Planning
in Parkinson's



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Summer 2023

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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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Message from our Executive Director

Dear friends,

I hope this edition of PULSE Magazine finds you enjoying a beautiful Alberta summer. Many of our friends were, and continue to be, impacted by either wildfires or the flooding that followed. Our thoughts are with all affected and we wish you quick and positive resolution.

Weather did not dampen the spirit of community that we enjoyed throughout the spring. Parkinson Awareness Month gave us the opportunity to elevate the voices of those living with or loving someone with Parkinson disease in Alberta. In addition to media appearances and small local events across the province, our friend Roger Dootson started off fundraising efforts by offering to match donations up to \$20,000. His generosity combined with that of so many in the community, including our educational presenter, the Brain Canada Foundation, resulted in over \$60,000 in support of the work of Parkinson Association of Alberta. We are so grateful.

We were thrilled to partner with the team behind the inspiring documentary "The Zone" in May, welcoming both the Parkinson's community and mountaineers for an exclusive premier and Q&A. In June, Cars for a Cause brought together car owners and enthusiasts in Edmonton and Calgary in support of Parkinson disease awareness. Our first ever Wellness Retreat took place at the end of June and we look forward to reporting back on this pilot event in the fall edition of PULSE.

At the beginning of May, we also launched the website for the 2023 Step 'N Stride Walk for Parkinson's. September 9th and 10th will see hundreds of people affected by Parkinson disease walking in 9 markets across Alberta. Who will you walk for? Our team has invited participants to share their stories to honour the loved ones who motivate their fundraising efforts.

"In 2003, our team attended its first Walk, and we haven't stopped since. This year's Step 'n Stride will be our 20th year walking as a team!

We walk in memory of Donald Victoor, who was diagnosed with Parkinson's at the age of 39, lived with the disease for 26 years, and passed away in 2004. His brother Doug was diagnosed with PD in 2006 and continues to maintain a positive attitude, lives an active lifestyle and participates in Step n' Stride each year.

Why are we called The Victoor Team? Simple – it's our family's last name, and our motto is "Walk, Run, Be Victoorious over Parkinsons." - Shauna Robertson, Team Victoor.

Registration is now open, and we are grateful to all who continue to make this event Parkinson Association of Alberta's most important fundraiser of the year, both in raising much needed funds and in celebrating this amazing community of support and the individuals who make it so special.

This edition of PULSE focuses on planning for the future. Advance Care Planning. This can mean different things for different people, but the commonality is that regardless of your age or personal circumstances, if you wish to have your voice heard in the event you are no longer able to, planning is necessary. Our team has pulled together some really great information and guidance and if you find yourself unsure of where to start, we are only a phone call away.

All the best for a peaceful summer.

Lana



The Power of CHOICE

Advanced Care Planning in Parkinson's



Written By: Brandi La Bonte

Advance Care Planning – those three words can sometimes make people feel uncomfortable or even fearful. This is largely due to the fact that many people think end-of-life care and advance care planning are one and the same. This is a misconception. Advance Care Planning and end-of-life care are NOT the same thing. End-of-life care is a PART of Advance Care Planning; but Advance Care Planning is so much more. In a nutshell Advance Care Planning provides people with the power of choice when you are unable to advocate for yourself.

Advance Care Planning (ACP) provides individuals with a framework to have greater independence, choice, and control over decisions relating to personal, medical, legal, and financial matters. Having this framework in place is especially important when diagnosed with a

progressive, chronic illness like Parkinson's which, at some point, progress in a way that limits or removes your ability to make decisions, advocate and/or speak up for yourself.

Unfortunately, many people face critical decision making at a time they lack the capacity to make decisions for themselves be it due to disease, accident, injury, cognitive decline, etc. In these instances, and without your plan in place, others (loved ones, medical professionals, or the judicial system) must step in to make decisions that THEY feel are the decisions they would have made for themselves or (if that cannot be determined) that THEY feel are in the best interest of the person. In these situations, the power to choose what is best for yourself is no longer yours.

There are four components of ACP framework: personal, medical, legal, and financial.

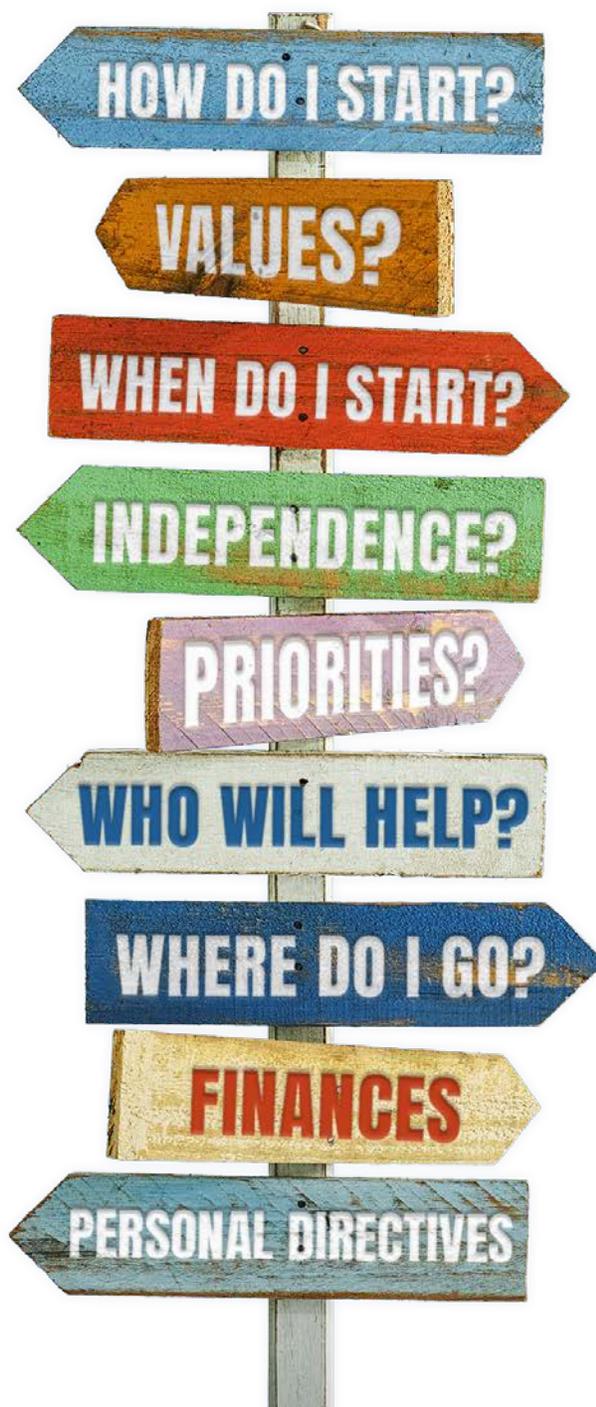
Medical (also referred to as Clinical) asks “What about my future care and treatment?” This covers your thoughts and decisions regarding health care decisions including medical care, comfort care, and resuscitative care. We cover this aspect in our Understanding Green Sleeves and Goals of Care Designation article.

Legal asks “What happens when I can’t make decisions myself?” and covers the carrying out of your medical and personal wishes (but not financial ones) when you can no longer make decisions on your own behalf.

Financial asks “What about my finances?” and address all your future financial plans and actions (i.e.: submitting your taxes, paying for your care, etc.). These two aspects are covered in the article Understanding Personal Directives and Enduring Power of Attorney.

Last, but certainly not least is the **Personal** aspect. This component of the framework focuses the bigger picture of your decision-making process asking “What matters to me? What are my values, wishes and beliefs?” This portion also asks you to consider your thoughts and choices regarding practical aspects of day-to-day life including driving and living arrangements, in addition to the medical, legal, and financial.

We understand getting started isn’t always easy. For some it can seem daunting or something to be dealt with later. We would encourage those hesitant to start to consider Advance Care Planning in a more positive light. This is independence, this is control – the power is in YOUR hands to make the best decisions for YOURSELF even when you can no longer advocate for yourself. For others the process is the easy part, the daunting part is ensuring loved ones are aware of our future choices and decisions. (We cover that in this issue as well!) Advance Care Planning ensures the **power of choice** is in your hands so that your choices and decisions are honored. More information is included in this edition of Pulse and if you’re not sure how to get started, we are here to help you navigate through the process of ensuring your voice continues to be heard.



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UNDERSTANDING PERSONAL DIRECTIVES AND ENDURING POWER OF ATTORNEY

Written by Brienne Leclaire

Planning for future possibilities can be difficult. While the future is unknown and ever changing, we can take steps to ensure we have some control over our own futures. Personal directives and enduring power of attorney forms are a part of this. Both of these forms give us a chance to outline our needs and wants for ourselves should we one day lose the capacity to make decisions temporarily or ongoing. It can be intimidating or even scary to think about the future, or you may think the future is far off and these documents are just for people already losing capacity. These documents are important for everyone of any demographic. Both are documents that can be updated and changed as your needs and wants change over time. Putting these together does not mean they take effect immediately and only come into effect when necessary. This article hopes to take some of the fear and unknown out of putting together both personal directives and enduring power of attorney forms.

Personal Directives

Let's start off with personal directives. A personal directive is a legal document that allows you to name the individual(s) (called your agent) you trust to make decisions on your behalf should you lose capacity. In this you will list the areas in which they have decision-making authority (e.g., health care, residential issues). You can include instructions that you want followed for nonfinancial decisions (for financial decisions see Enduring Power of Attorney) (e.g., refuse blood products, life support), as long as it does not include anything illegal or revolve around financial decisions. Your instructions can be about any or all personal

matters that are not financial, such as: medical treatments you would or would not want, where you would like to live, who you would like to live with, who will care for your children (if they are minors), choices about other personal activities for example recreation, education, any other personal and legal decisions. Some decisions for example a do not resuscitate order or organ donation require additional paperwork to be filed.

Personal Directives can be short or long term. For example, if you are in an accident and health decisions need to be made for a few days or long term for

example in the case of dementia. If you want to choose who your decision maker is, write a personal directive and name an agent. Otherwise, under the Adult Guardianship and Trusteeship Act, a health care provider may select the nearest relative to make decisions for a person who is assessed as being incapable of providing informed consent for health care or temporary residential placement at that time.

To be considered a legal document, the requirements are that your personal directive must be in writing (by hand, typed or digital form), dated, and signed by you in the presence of a witness. The following persons cannot witness the signing of a personal directive. Any person you have selected to make decisions on your behalf – called your “agent”, the spouse or partner of your agent, your spouse or partner, and the person who signs the directive on your behalf. If you are physically unable to sign the directive, another person must sign on your behalf in the presence of a witness and in your presence.

Although it is not a legal requirement to do so, it is a very good idea to give a copy of the directive to your agent, physician and to other service providers with whom you are involved (e.g., the director of the nursing home where you live). This ensures these individuals are aware of your directive and agent.

Enduring Power of Attorney

Enduring power of attorney is similar to a personal directive, however instead of covering health and residential decisions it covers financial decisions while you are alive. Generally enacted in the event you lose or have diminished capacity to make decisions. An enduring power of attorney is a legal document that you make to give another person (referred to as attorney) the authority to make financial decisions on your behalf. The document is written when you are capable of making your own decisions and states when the person will have authority. An enduring power of attorney can start either immediately and continue if you lose capacity or start when you lose capacity. If you lose your capacity and do not have an enduring power of attorney one of your family members or friends might have to go to court to become your trustee. This can take a lot of time and can be a costly process.

There are no standard forms for creating an enduring power of attorney. While having a lawyer help create your enduring power of attorney is not mandatory it is safest way to make an enduring power of attorney. This is to make sure you have protected all your financial interests and that your enduring power of attorney is legal.

Your enduring power of attorney lasts until one of the following occurs you pass away, you revoke or cancel it, court order reflects it is no longer valid, a court grants a Trusteeship order, your attorney dies, quits or an order of Trusteeship is granted over that person where there is no alternate attorney.

Once your enduring power of attorney is enacted your attorney deals with your day-to-day finances. They will have the power to prepare and submit tax documents, pay for medical care and support, use your assets to pay maintenance or spousal and child support, hire people to help you, deal with business interests and investments and other relevant financial day-to-day matters. Your attorney cannot buy or sell your home or any other real estate property belonging to you, (unless you specifically give them this power), cannot change or make a new will for you, cannot make, or change your enduring power of attorney, and cannot change beneficiaries on investments, RRSP plans, pensions or life insurance policies.

Just like personal directives it is a good idea to make sure you give a copy of the enduring power of attorney to your attorney, physician and to other service providers with whom you are involved (e.g., your lawyer, the director of the nursing home where you live).

In the event you wish to revoke or change your enduring power of attorney the steps to take will depend on your enduring power of attorney and capacity at that time. If you have capacity, you can revoke your enduring power of attorney at any point and for any reason. When you wish to revoke or change your enduring power of attorney immediately inform your attorney they are no longer permitted to act as your attorney. You then need to inform other people that you have involvements with like your bank, accountants, and lawyers.

If you do not have capacity, any party, or any interested person can apply to the courts for a full accounting of all dealings by your Attorney. Once the court is satisfied an order for action or adjustment will be granted. From there adjustments will be made in accordance with the courts ruling. In the event a new attorney is needed, and you do not have capacity a trusteeship will need to be put in place. The courts cannot name a new attorney for you. The judge may suggest a proceeding for the application for trusteeship. An interim order for trusteeship can be granted at that time until an ongoing trusteeship can be put in place.

These two aspects of advance care planning aim to ensure you are able to make the best decisions for yourself in the event you are no longer able to advocate and/or speak for yourself.



WHY RESEARCH MATTERS

ADVANCED CARE IN PARKINSON'S DISEASE AND RELATED DISORDERS

*Written By: Dr. Karla Cantu-Flores & Dr. Veronica Bruno
ACT-PD – Movement Disorders Program – University of Calgary*

Despite the ongoing scientific efforts dedicated to discovering effective treatments that can decelerate the advancement of Parkinson's disease and atypical Parkinsonian syndromes (PDRD), many individuals worldwide receive the diagnosis and encounter daily challenges associated with these conditions¹. The impact extends not only to the patients themselves but also to their caregivers and families, who must also adapt to life with these diagnoses.

In the advanced stages of PDRD, individuals living with the condition and their caregivers face significant difficulties that significantly affect their lives². These challenges include motor and non-motor problems, such as cognitive changes, hallucinations, frequent falls, and constipation. Planning for care becomes particularly challenging during this stage due to the unpredictable nature of the disease's progression. In addition, while healthcare providers focus on reducing symptom burden, advanced patients and care partners also deal with difficult emotions such as demoralization and grief³.

Recognizing and assisting patients and care partners

throughout this journey is paramount. Regrettably, there has been limited exploration thus far into the specific needs and potential benefits of various interventions for individuals living with advanced PDRD and their care partners. There is a significant need for robust research to understand better and identify the most effective strategies for enhancing patients' and care partners' quality of life.

In a collaborative research study conducted with the University of Alberta, we have recently published an insightful investigation into the healthcare experiences of individuals with PDRD during their final year of life in Alberta. Our findings shed light on these patients' challenges and underscore the urgent need for a comprehensive and compassionate program to support them in their journey.

Our study included a sample size of 1429 individuals diagnosed with Parkinson's disease, Progressive Supranuclear Palsy, Multiple System Atrophy, and Huntington's disease, among others. The results revealed that approximately half of these patients passed away in hospital settings, while two-thirds

experienced hospital stays and emergency room visits during their final year. Less than 10% of these individuals received the palliative and end-of-life care required during this critical period⁴. The absence of Advanced Care Planning conversations among individuals with PDRD is undoubtedly a significant factor contributing to the findings we described. When there is no well-established plan, making decisions during the end-of-life period becomes incredibly challenging. Unfortunately, many individuals with PDRD do not have the opportunity to express their healthcare wishes when confronted with emergencies. This issue further emphasizes the importance of facilitating these conversations to ensure patient preferences and goals are respected and honored during these pivotal moments. By engaging in Advanced Care Planning, we can strive to improve the quality of end-of-life care for individuals with PDRD, empowering them to have their voices heard and their wishes fulfilled.

The findings of our study have brought to light a distinct gap in the care provided to individuals with PDRD, highlighting the urgent need for establishing a comprehensive program in Calgary that specifically addresses advanced care for PDRD patients. In response to these pressing needs, we launched the Advanced Care Team for Parkinson's (ACT-PD) pilot program in October 2022. The primary goal of ACT-PD is to provide earlier access to multidisciplinary advanced care in PDRD while offering personalized support to both patients and their care partners. The ACT-PD team consists of a neurologist, a registered nurse specializing in advanced care, a psychologist, a community liaison, a spiritual care provider, and a research coordinator. Working collaboratively, our team is committed to delivering comprehensive care that caters to the unique needs of patients and caregivers alike.

Through the ACT-PD program, we aim to improve the quality of life for individuals with Parkinson's disease and related disorders, ensuring they receive the holistic support and specialized care they deserve. The ACT-PD program operates on a clinical research model,



with scheduled visits every three months to provide ongoing care and support. Additionally, the program includes follow-up phone calls one and six weeks after each visit, ensuring a clear understanding of the team's recommendations and offering continuous support. To facilitate communication, patients and care partners have direct access to a dedicated phone line and email for any emerging concerns or questions. Currently, the program operates one full day each week at the location of the Movement Disorders program. This schedule allows for dedicated time and resources to be allocated to the comprehensive care and assistance provided to patients and their care partners within the ACT-PD program.

During the two-hour visits, the ACT-PD team assists patients with various concerns. This includes managing their symptoms effectively, establishing personalized goals for their care, addressing emotional well-being, and supporting their care partners. The team strives to offer the best available treatments for physical and non-physical symptoms while aiding patients in planning and providing spiritual support. Mental health assessments are conducted, and counselling sessions are tailored to meet the specific needs of patients and caregivers. Furthermore, the ACT-PD team is crucial in connecting patients with community resources, such as home care services, speech therapy, and financial assistance.

From a research perspective, our primary objective is to demonstrate that this comprehensive and integrated approach to care can significantly enhance the overall experience of patients and care partners, thereby improving their quality of life. Additionally,

Why Research Matters: Advanced Care in Parkinson's disease and Related Disorders

we are committed to ensuring that everyone involved receives education and support regarding advanced care planning, thus ensuring that their wishes are fully expressed and respected.

We aim to provide comprehensive care that addresses the diverse needs of patients and caregivers while also generating valuable research insights to support further advancements in PDRD.

Since its launch, the ACT-PD pilot program has met and exceeded expectations. Initially aiming to recruit 50 participants over two years, the program experienced an overwhelming response within the first six months. In the first six months alone, the ACT-PD team successfully served more than 50 individuals with PDRD and their dedicated care partners.

The overall preliminary results of the intervention showed promising improvements across multiple areas. Participants' satisfaction rates increased, indicating greater contentment and fulfillment. The quality-of-life measurements also showed improvement, suggesting a positive impact on participants' well-being⁵. Care partners experienced a reduced burden, as evidenced by lower Zarit Burden Interview-12 scores⁶. Moreover,

the completion rate of goals of care significantly increased, with 95% of patients actively engaging in educational conversations.

In light of our research study findings and the remarkable accomplishments of the ACT-PD program, it is evident that this holistic approach plays a pivotal role in ensuring a dignified and meaningful end-of-life journey for individuals living with PDRD. Future imperative steps include conversations among healthcare institutions, policymakers, and the community to collaborate and work together. By expanding access to specialized care and implementing comprehensive support systems, we can ensure that individuals with PDRD receive the necessary assistance, comfort, and respect they deserve during the final stages of their disease. Through collective efforts, we can make a profound difference and create a compassionate and inclusive environment that supports the well-being of patients with PDRD and their caregivers in Alberta.

Contact information:

M: actpd@ucalgary.ca

P: (403) 210 7542

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PROGRAM NEWS & UPDATES

Summer Socials

During the month of August, come on out and join us for one of our 24 summer socials across the province. It's a chance to enjoy the sun and fresh air, while relaxing and connecting with friends, and seeing new and familiar faces! Call or email to register.

Step 'n Stride Kickoffs!

Please join us as we kick off Parkinson Association of Alberta's 11th **Step 'n Stride**. Everyone is welcome to come out for a BBQ and register. There will be staff available at each SNS Kickoff to answer questions and assist with registration. Check out our website to find the Kickoff nearest you!

Step n' Stride September 9 and 10, 2023

This year is our 11th Step 'n Stride weekend, as we continue to raise awareness and support for those impacted by Parkinson disease and Parkinson Plus Syndromes. Go to www.stepnstride.com for updates on the walk in your area, registration, FAQ's, and fundraising incentives. It is a chance to get together with friends and family, play some games, be entertained, have some food and treats, and enjoy the fresh air and sunshine, while supporting those we love and care for.

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

WHAT'S NEW?

Important Dates to Remember

All PAA Offices will be closed on the following dates:

July 3 (in lieu of Canada Day)

August 7 Heritage Day

September 4 Labour Day

September 9 & 10 –
Parkinson's Step 'n Stride

September 30
Truth & Reconciliation Day

October 9 Thanksgiving

October 25-27
PAA In-Person Staff Meetings



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IT'S PERSONAL

MEDICAL ASSISTANCE IN DYING (MAID)

Written By: Sherry Bower-Gagne

Knowledge is power and our goal at the Parkinson Association of Alberta is to keep you up to date and informed on topics of interest and importance to those we serve, even if those topics seem daunting or difficult.

While not every aspect of advance care planning is about end of life, that is a part of it as well. One of those end-of-life topics is medical assistance in dying (MAID). A topic that has been discussed for decades, MAID is a complex and deeply personal issue. Often it is one that runs through our heads when we feel helpless as we witness a loved one go through a painful or prolonged illness. For some, it is wishing for the physical or emotional pain to stop.

In June 2016 Canadians gained the right to ask for medical assistance in dying (MAID). In August of that year my husband was diagnosed with bone cancer that had spread to his brain. He spoke with his health care team and began his application. October 19, 2016, he

died with medical assistance. Since that time over 2600 Canadians have received MAID.

My husband was a logical and caring man, and there were so many reasons for his decision. He spoke with his medical team, then shared his wishes with me. We discovered that not all medical professionals agree with MAID, however it is their responsibility to provide resources and contact information for those who request it. We share this personal experience with you, not to tell you what to do or to influence your decision – rather to acknowledge that we understand how deeply personal this decision can be. The option to choose MAID will not be right for everyone for various reasons; but it is an option none-the-less and in keeping with our goal to keep the Parkinson's Community up to date and informed we are discussing it here today.

In this article we will cover the some of the most frequent questions asked.

What is Medical Assistance in Dying?

Medical Assistance in Dying or MAID refers to the situation when a person seeks medical help to end their life. In the past it has also been referred to as “assisted suicide” or “physician-assisted suicide.” There are two medical procedures to complete the process of MAID, oral and intravenous. In this article we will discuss intravenous.

What is the difference between MAID and Palliative Care?

Palliative care focuses on improving quality of life and managing symptoms to help people live and die well. MAID aims to ease the suffering by aiding an eligible person end their life with assistance by trained clinicians by administering medications that lead to death.

Who can access Medical Assistance in Dying (MAID)?

On March 17, 2021, new legislation regarding MAID was put forward and became law. These changes introduced a two-track approach. What this means is that an individual does not need to have a fatal or terminal condition to be eligible to apply for Medical Assistance in Dying. The changes include a broader group of people that are eligible, and now include individuals who have a grievous or irreversible medical condition. This means that an individual who has a serious illness, disease, or disability can now access the service (this does not include mental illness currently). If they are in an advanced state of decline which can not be reversed, they are experiencing unbearable physical or mental suffering from their illness, disease, disability, or state of decline that cannot be relieved under conditions that they consider acceptable, their application will be considered.

To be eligible for MAID an individual must meet all the following criteria.

- » Be eligible for health services funded by the federal government, or a province or territory (or during the applicable minimum period of residence or waiting period for eligibility).

- » Be at least 18 years old and mentally competent. This means being capable of making health care decisions for themselves.
- » Able to make a voluntary request for MAID that is not the result of outside pressure or influence.
- » Able to give informed consent to receive MAID. The person must provide informed consent to their practitioner. This means that they have given consent (permission) to MAID after they have received all the information needed to make their decision. This includes their medical diagnosis, available forms of treatment and have been informed of the available options to relieve suffering including palliative care.
- » The individual must be able to give informed consent both at the time of their request and immediately before MAID is provided. **The changes to this legislation made on March 17, 2021**, allows final consent just before MAID to be waived. The **Advance Consent Arrangement** allows for the **Waiver of Final Consent**. Safeguards were put in place that apply to someone seeking MAID to be able to consent in advance to it even if they have lost decision making capacity by their chosen date for the procedure.



Who can I talk to about medical assistance in dying?

The place to start is to speak with a doctor or nurse practitioner. If an individual does not have a regular family doctor or they feel that their physician will not be supportive, there are options. While health-care professionals are not required to participate in MAID, they are responsible to provide patients who ask with resources and contact information in their province or territory for the Health Services Medical Assistance in Dying Care Coordination Service.

It's Personal: Medical Assistance in Dying (MAID)

The Medical Assistance in Dying Care Coordination service offers support for patients, families, and health-care providers. They can be reached through email MAID.CareTeam@ahs.ca or by calling Health Link at 811.

What does the process look like?

Starting the MAID Process: If one wishes to request MAID, the first step is to visit a doctor/physician or nurse practitioner and request information on MAID. The physician will send a referral for MAID to the MAID nurse navigator. An individual can also reach the MAID Care Team through email MAID.CareTeam@ahs.ca or by calling Health Link at 811.

The MAID Nurse Navigator (MNN) will connect with the individual to move to the next step, where the individual will sign the MAID consent form in the presence of two independent witnesses. The MNN will connect with individual for an interview, intake, and to explain the process. They will keep in contact with the individual and their circle of care in case their health status changes.

The MAID assessment: At this point the MAID Nurse Navigator has sent the MAID documentation to the first clinician who will determine whether the individual meets the eligibility criteria. If the individual meets the criteria, they move on to the second and possibly third clinician for assessment. An assessor will arrange a date and time with the individual. The 10-day waiting/reflection period begins, or they can choose to wait and contact their team if/when they choose to move forward at a later date.

Maid Preparation: Three options are available for individuals who choose to access MAID. Options include Hospital in Patient, Hospital Outpatient and

Non-Hospital where an individual may choose where they wish to have the procedure completed (i.e.: at home).

Day of MAID: The physician and clinician arrive at the location; they will assess the patient for capacity and obtains consent for MAID; unless the individual has made an **Advance Consent Arrangement** that allows for the **Waiver of Final Consent**. For those who do not have an **Advance Consent Arrangement**; at this time the patient may choose not to have MAID. On confirmation of the decision to proceed, the medical professionals present will administer a process that is designed for the comfort of both the patient and family present. The specific details of this process will be discussed in advance with your health care provider.

Post MAID: After death, the family will have time with their loved one. Depending on whether the procedure was completed in or out of hospital the next steps will vary.

What about my spouse and loved ones afterwards?

The loss of a loved one is never easy. Dealing with an illness and death of a loved one is incredibly hard. We never know how we will cope or react until we are in that moment. For me I know that having my loved ones close to me to lean on made the loss of my husband bearable. We each deal with our grief in our own personal way, and we know there are supports available. The Medical Assistance in Dying Care Coordination service offers support for families, and Parkinson Association of Alberta is here for you every step of the way.

Sources

Medical Assistance in Dying – Alberta Health Services <https://www.albertahealthservices.ca/info>

Dying With Dignity Canada <https://www.dyingwithdignity.ca/about-us/>

Government of Canada- MAID and the Law <https://www.justice.gc.ca>

Palliative and end of life Care <https://www.albertahealthservices.ca>

Canadian hospice palliative care association <https://www.chpca.ca>

Grief and Bereavement <https://myhealth.alberta.ca/HealthTopics/Palliative-Care/Pages/Grief-and-Bereavement.aspx>

**There are more than
1,000 brain diseases and
disorders out there.**

**It only takes 1 reason
to support research.**

What's yours?



braincanada.ca/donate

Janelle Drouin-Ouellet is a Brain Canada-funded researcher studying the effects of aging on the brain, providing insights into new treatments for diseases like Parkinson's and Alzheimer's.



APPROACHING DIFFICULT CONVERSATIONS

Written By: Sherry Bower-Gagne

Inevitably as Parkinson's progresses or as our loved ones' age we may find ourselves needing to have conversations about getting more help, driving abilities, safety concerns, moving into a retirement community or care facility, end-of-life decisions, or other difficult topics. Understandably these are not always easy conversations to have, however they are necessary ones – to keep yourself or your loved one(s) healthy and safe, reduce strain and stress on a care partner, or even for a family's peace of mind. Important to note here is that it is not JUST conversations with aging parents or those with Parkinson disease that this article refers to; it also includes adult children. It can be just as difficult to relay decisions about health, safety, and well-being concerns to adult children as it is for adult children to raise concerns to their loved ones.

So how do you talk to your spouse or your aging parent(s) about concerns regarding their safety, health, or quality of life? Or to adult children about decisions, you have made regarding your own future? In this article we will talk about how to begin those uncomfortable but important conversations.

Talking to your spouse/aging parent(s)

Have the conversation as early as possible. Rather than having a health crisis force making a decision in which your loved one will have little say, have these important conversations early. Having the conversation BEFORE there are safety, health or well-being concerns can take the pressure off making immediate decisions, allow time for your loved one(s) to learn about and consider all options, and make the best choices for themselves. The same applies to sharing your wishes regarding your future (be it selling the house, medical decisions, or end-of-life) with adult children; the earlier you start the conversation the more time you give your loved ones to share their thoughts and accept your choices.

Having the conversation early also makes it possible to **have multiple conversations** and **take a break from the conversation**. Many of the more difficult conversations result in a HUGE change and/or loss of independence for some. The probability of coming up with solutions to potentially emotional decisions in one

conversation is likely not possible. This is a process, not a one and done discussion. This may take a series of talks.

Conversations about future plans you have made, or safety, health, and well-being are not always welcomed with open arms; in fact, it can be the opposite where a loved one(s) feel blind-sided, attacked, condescended to, or hurt. This is yet another reason to have the conversation early when issues are either not present, or not pressing. This isn't always possible of course; but whether you have the conversation in advance or in the moment there are a few things as the "Conversation Initiator" you need to consider.

Are you prepared for the conversation? Do you have an idea how your loved one(s) feel about any particular topic? What is their typical conversation style? If you are an adult child, are you fully aware of what the day-to-day of your loved one(s) is? Have you thought about what your concerns are? As you consider these questions it may be beneficial to create a list of your concerns. For example, are you worried that driving long distances or at night is no longer a safe environment for them? Have their health conditions become more difficult for them or you as a couple to manage? Are they having trouble with activities of daily living, such as dressing, bathing, or managing their medications? Is the spouse/care partner struggling to manage their own health and well-being as well as their loved ones? Are there more falls? Are issues with cognition that may make it unsafe? Discussing concerns with other family members or peers (other care partners or adult children) and getting their perspective may bring more awareness, though it is important not to "gang up" on your loved one(s). Write down observations so that you are able to keep on track and focused, these types of conversations are sensitive and often emotional.

Taking the time to **educate yourself** and learn more about supports and solutions to identified safety, health, and well-being concerns can give you the confidence and the credibility you need to begin the conversation. Once you learn more and feel more confident about the options you will be able to have a genuine, constructive conversation. Keep in mind that exploring and learning gives you options to share and discuss, it does not mean that you are making the

final decisions. By preparing yourself with possibilities to share, you will be able to offer options to concerns that may lay ahead. By discussing options, you will help your loved one keep some control over their life and be as helpful as possible for the conversations and decisions ahead.

Talk in person, if possible. Face to face conversations are always the best option, if not a video call so you are able to see each other during the discussion. Choose a time when all involved are rested and more relaxed; and location where you can talk without being interrupted.



It is so important to **listen to your loved one.** Recognizing and admitting that things have changed or progressed, that they might not be able to do what they once did, or that they or their loved one needs more specialized assistance than you/they are able to provide isn't easy. It is a loss. A loss of independence, a loss of sense of self, a loss that can take time to come to terms with. There will be anxieties, concerns, worries, and (in some cases) objections. It is important to acknowledge these feelings, not minimize them. Asking questions in an empathetic and calm manner will show that you care and are trying to understand the fears and frustrations they may feel. By trying your best to put yourself in their shoes it will come from

Approaching Difficult Conversations

a place of empathy and the conversation will have a caring tone versus controlling. It may not change the outcome of the end decision, but it will help your loved one know that they have been heard and respected.

Remember, it is their decision. Unless your loved one or you are a danger to themselves or others, or your health is compromised (care partners, this means you too) it is up to them to make choices they deem best for themselves. Voicing concerns and asking questions is natural and healthy if done in a respectful and non-coercive manner; however ultimately the choice is theirs to make.

Starting that conversation. Beginning the discussion is the hardest part, open ended questions are the best way to encourage conversation. Here are some conversation starters.

- » How is it living at home alone?
- » Do you still feel safe? (This might include stairs, taking medication, safety in the bathroom, kitchen or outdoors)
- » Have you thought about support coming into the supported living or long-term care? For example, if you (or I) fell or got sick and couldn't take care of yourself or I wasn't able to help with what you needed?
- » How would you or we pay for it?
- » Ever wonder about getting a helping hand with housekeeping and laundry?
- » Would you feel less stress if you didn't have to worry about the house?

Talking to your adult children

In the previous section we talked about initiating the conversation sooner rather than later. The same applies to sharing your wishes regarding your future (be it selling the house, medical decisions, or end-of-life) with adult children. The earlier you start these conversations the more time you give your loved ones to process and become accustomed to your decisions. As before, depending on the decision or decisions this likely isn't just one conversation, rather an ongoing conversation over time.

It can be challenging and emotional for adult children (or other loved ones) to engage in conversations about end-of-life and/or accept the reality of your changing needs and progressing Parkinson's. This is anticipatory grief and is natural for a parent-child relationship as the parent ages.

Understanding your adult child/children's communication style can help you prepare to initiate the conversation. Is it a one-on-one conversation? Is it a family-style meeting? Making yourself notes on what you want to say/share can be helpful in keeping you on track. Your family may have questions or in some cases be resistant to your decision. Everyone is entitled to their own feelings. Questions are often a person's way of understanding, so considering questions asked purposefully and thoughtfully can go a long way. That said these are YOUR decisions, wishes and choices and you should not be persuaded, coerced, or guilted into changing them.

An IMPORTANT note on that last sentence. We all know life happens and things change, so it is important to understand that some of the choices you determine early on, may not be feasible in the future and as such new plans and/or conversations may need to be had. For example, you may want to stay at home and not move into a retirement community or care facility; however, declining health/cognition may make it unsafe to stay at home or put your loved one at increased risk of stress, burn out, or injury.

Finally, a caution on information/conversation overload. Sharing information upfront can be helpful, however a lot of information all at once may be overwhelming. It is a human reaction when feeling overwhelmed to become defensive. It will put an end to that conversation and make it difficult to start again. As mentioned earlier it is best to have multiple, smaller, meaningful conversations over time, allowing the information to sit and be processed and pick it up again later.

As Desmond Tutu wisely said, "there is only one way to eat an elephant: a bite at a time." What he meant by this is that everything in life that feels overwhelming and even impossible can be gradually accomplished by taking on a bit at a time rather than taking on the whole thing all at once.



UNDERSTANDING GREEN SLEEVES & GOALS OF CARE DESIGNATION (GCD)

Written By: Emma Torneiro

The initiation of advanced care planning can be overwhelming and daunting due to the common association with end of life, the unfamiliarity with the tools needed for advanced care planning, or difficulty starting the conversations around planning for the future. However, it is important to plan for our futures, including outlining our medical choices. One of the best places to start the process is with the completion of your Green Sleeve and Goals of Care Designation documents.

Green Sleeve

The Green Sleeve is defined as an individual medical passport, recognized by Alberta Health Services, containing essential documents for advanced care planning. The documents within the Green Sleeve outline your choices on future medical and healthcare decisions in the event you are unable to advocate for yourself; this could be due to communication or cognitive issues as an example. These future medical and healthcare decisions can include choices such as where you want to reside as you age (at home, assisted living, long-term care etc.), what life-saving medical procedures you would want, guidelines for medical decisions, and information on the most important aspects for you regarding quality of life.

The Green Sleeve is used for emergency situations, situations involving the inability to advocate for yourself, medical decisions once a Personal Directive is enacted, or situations involving changes to capacity for decision-making processes. The Green Sleeve can include the Goals of Care Designation order, Advanced Care Planning/Goals of Care Designation Tracking Record, a copy of your Personal Directive, a copy of Guardianship Orders, and Expected Death in Home form. Once the updated forms have been placed in the Green Sleeve, it should be stored on/near the fridge, where first responders are trained to look for it. The Green Sleeve will be transported with you to hospital during emergency situations or can be brought to important medical appointments with you.

The Green Sleeve is an important document for all Albertans over the age of 18 to have in place. The documents are filled out in partnership with your healthcare team and shared with family members or agent(s) listed in your Personal Directive. The Green Sleeve is extremely important to complete to ensure your healthcare and medical wishes are known and followed by health care providers in any setting. The documents provide health care professionals direct access to your goals of care, directions for interventions, and future medical decisions when you are unable to

Understanding Green Sleeves & Goals of Care Designation (GCD)

self-advocate. It is important to complete the Green Sleeve early, before an emergency, to ensure you have sufficient time to reflect on your decisions and reduce the potential stress that can be associated with the process of advanced care planning.

If you don't have a Green Sleeve, contact us at 1-800-561-1911 to request one.

Goals of Care Designation (GCD) Order

The Goals of Care Designation order, which is stored within the Green Sleeve, is a medical order form stating your general care wishes, location of care, and transfer options for care in Alberta. The order is completed with and signed off by a healthcare practitioner overseeing your care (e.g., family physician or neurologist), who will provide expertise to assist in selecting the level of care within the medical order that aligns with your individual values, beliefs, and future care choices. The conversations with your healthcare team related to the Goals of Care Designation order are tracked using the Advanced Care Planning/Goals of Care Designation Tracking Record and stored within the Green Sleeve for future reference. The Goals of Care Designation acts as an instructional communication tool between yourself as the patient and the healthcare team providing care when you're unable to self-advocate. The order guides healthcare teams to provide timely care that aligns with your pre-determined medical choices and personal values. It is recommended that the Goals of Care Designation order be completed early, similar to the Green Sleeve. The document should be reviewed and updated if new health concerns arise, or if there are significant changes to current health concerns. As Parkinson's is a progressive neurodegenerative disease, the Goals of Care Designation and Green Sleeve should be updated regularly to accommodate changes that occur with the disease.

The Goals of Care Designation order contains three (3) levels of care:

- » Resuscitative (R),
- » Medical (M), and
- » Comfort (C).

References

Alberta Health Services. (2023). *Frequently Asked Questions Advanced Care Planning/ Goals of Care*. Alberta Health Services. <https://www.albertahealthservices.ca/info/Page15938.aspx#whatgcd>

Palliative and End of Life Care Team, AHS. (April 2, 2018). *Goals of Care Designations*. Government of Alberta. <https://myhealth.alberta.ca/health/Pages/goals-of-care-designations.aspx?hwid=fdmostSgkM>

Palliative and End of Life Care Team, AHS. (April 2, 2018). *Green Sleeve*. Government of Alberta. <https://myhealth.alberta.ca/health/Pages/green-sleeve.aspx?hwid=TFiJW8-S9c4>

The levels are further categorized by 2-3 levels according to the medical procedures included within each.

The level of Resuscitative Care focuses on life-sustaining care and prolonging life by curing or controlling health conditions, when possible and when beneficial. The level includes diverse intensive medical and surgical interventions, including cardiopulmonary resuscitation (CPR), life support interventions such as a ventilating machine, admission to the Intensive Care Unit (ICU) for treatment, and medications to manage medical condition(s).

The level of Medical Care focuses on prolonging life and management of treatable health conditions without the use of resuscitative supports or admission to the ICU. The M level is utilized when intensive interventions (e.g., CPR) are unlikely to work or unlikely to restore health to previous state. The level includes fewer intensive treatments, such as blood transfusion, feeding tubes, or the use of medication.

The final level, Comfort Care, focuses on the implementation of care, interventions, and medical treatments that provide comfort, relief, and support to reduce symptoms. The C level does not include resuscitative treatments or cure medical conditions. In contrast, the level could include medical treatments for pain or difficulty breathing. The C level is commonly associated with palliative care and occurs in a variety of settings, such as ICU, hospice, long-term care facility, or in home. The primary focus of level C is preparing for imminent death and maximizing comfort during this time.

The conversations surrounding advanced care planning can be difficult to navigate and challenging to share with loved ones. The completion of the Green Sleeve and Goals of Care Designation order can be the initial steps to successfully planning for the future to advocate for your healthcare wishes and ensuring the medical decisions align with your personal values, beliefs, and ideas on quality of life.



Join us September 9 & 10 across Alberta

WHY WE WALK

Step 'n Stride is our largest fundraiser of the year and accounts for over 20% of our annual budget. Last year, we raised over \$325,000 for our Parkinson's community, and hope to raise \$400,000 in 2023!

We walk at Step 'n Stride to help raise awareness of Parkinson disease and Parkinson Plus Syndromes, which affects more than 1 in 500 people across Canada, and more than 15,000 Albertans. We walk at Step 'n Stride to help raise the funds needed to deliver the programs and services our communities have come to depend on.

WHO IS STEP 'N STRIDE FOR

Step 'n Stride is for everybody! These are all-ages events, with activities for everyone. Registering for an event does not mean you have to come out and walk with us; we'd love to have you come and cheer us on, and enjoy the fun, fellowship and food.

WHO ARE YOU WALKING FOR

Our Parkinson's Community have been walking with us for 11 years. We've created memories, shared experiences, and inspired connections. This year we want to know Who Are You Walking For and share stories to inspire our community to register for Step 'n Stride 2023. We hope to create a close-knit community and spread awareness for those affected by Parkinson disease.

WHEN TO REGISTER

The sooner you get started, the more money you will be able to raise. Our fundraising platform has many interactive tools to help you connect with your contacts and donors, and the more time you give yourself, the better.

Start your team today, and begin planning your fundraising strategy!

WHERE CAN I WALK

Step 'n Stride takes place in 9 locations across Alberta, but where you choose to walk for Parkinson's is up to you! We would love to see you at one of our events, but whether you and your family walk around your local park, walk your neighbourhood, or event just walk the halls of your building, you'll be walking with us, and for us!

Sign up for **Step 'n Stride DIY** for your at home kit that lets you participate in Step 'n Stride in your own location and own time.



“ We are George’s Joggers. We are made up of family and friends who came together to support my dad, George Whitehead, who was diagnosed with Parkinson’s in the early 2000’s, in his early 60’s.

This will be our 20th year walking, and although we lost dad in 2011, we still walk in his memory. Our “Why” is to honour him, and all other people affected by this debilitating disease. We continue to raise awareness through our walk campaigns and have hopes for advancements in treatment, and one day a cure. We raise money for research and support programs for those living with Parkinson’s and their caregivers.

”

MARK YOUR CALENDARS

Saturday, September 9

Calgary

South Glenmore Park

Registration: **9AM** Walk: **10:30AM**

Edmonton

Rundle Park ACT Centre

Registration: **9AM** Walk: **10:30AM**

Red Deer

The Golden Circle, 4620 - 47A Ave.

Registration: **9AM** Walk: **10AM**

Lethbridge

Henderson Lake Park, Kinsmen Shelter

Registration: **9AM** Walk: **10AM**

Lloydminster

Bud Miller Park

Registration: **9AM** Walk: **10AM**

Sunday, September 10

Camrose

Grand Drive Park

Registration: **1PM** Walk: **2PM**

Cochrane

Mitford Park

Registration: **1PM** Walk: **2PM**

Grande Prairie **NEW TIME!**

Muskoseepi Park, Ernie Radbourne Pavilion

Registration: **9AM** Walk: **10AM**

Medicine Hat

Kin Coulee Park

Registration: **1PM** Walk: **2PM**

Register today at
www.stepnstride.com
or scan the code

