

UPCOMING EVENTS

- **Let's Get Loud and Clear** | Thursdays, June 1, 8, 15, & 22
Learn more & register: <https://bit.ly/loudclear-june23>
- **Rhythm in Motion (Level 3)** | Tuesdays, June 6, 13, 20, & 27
Learn more & register: <https://bit.ly/rhythm3-june23>
- **Debriefing the Caregiver Role** | Thursday, June 15
Learn more & register: <https://bit.ly/debrief-june23>
- **Popping for Parkinson's** | Mondays, August 21, 28, September 4, 11, & 18
Learn more & register: <https://bit.ly/popforPD-23>

UPCOMING FUNDRAISING EVENTS

Champions for Parkinson's

- Donate a Car Canada: Ongoing (read more: <http://bit.ly/2ORTuJn>)

We are looking for more Champions!

Do you want to help fund research, grow support networks, and improve quality of life for those living with Parkinson's disease (PD)? Become a Champion for Parkinson's and plan your own independent community fundraising event! Contact us at events@parkinson.bc.ca or 1-800-668-3330.

Register now for SuperWalk

Beginning the weekend of September 10 and 11, incredible British Columbians in more than 20 communities throughout the province will walk together to help give hope to approximately 15,000 people in BC living with Parkinson's disease. We invite you to join us for our largest fundraiser of the year, SuperWalk in a community near you. [[learn more and register](#)]

TIP JAR

The Tip Jar is where we share advice from Parkinson's community members on a wide range of topics from daily lifestyle hacks to safety. This month we share a tip on travelling!

When preparing to leave for a trip, ensure to be disciplined with your medications few days leading up to your date of travel. This way, the on and offset of PD symptoms will be more predictable for the duration of your trip.

Do you have any tips or tricks that you would like to share with the Parkinson's community? These can be tips from something that works well, to eating and dressing, to getting out of bed or travelling! All tips and tricks are welcome! Please share your ideas at info@parkinson.bc.ca.

NEWS & ANNOUNCEMENTS

Second DBS neurosurgeon hired

Dr. Stefan Lang has been hired as BC's second neurosurgeon for deep brain stimulation surgeries, addressing long wait times for Parkinson's patients. The move aims to improve access to the life-changing surgery and better support health outcomes for people with Parkinson's. [[learn more](#)]

Now Hiring

Join our team at Parkinson Society BC as an Education & Support Services Coordinator. This position plays a vital role in the delivery of information and educational resources to clients, supporting events, and providing guidance to support groups. [[learn more](#)]

June 10 is Action Anxiety Day!

Anxiety Canada is hosting Action Anxiety Day on June 10, 2023, which promotes the destigmatization of anxiety and aims to make treatment more accessible for everyone. As anxiety can be common in the Parkinson's community including individuals with Parkinson's, caregivers, and healthcare professionals, it is important to raise awareness and show support. Learn more on Anxiety Canada's [website](#) and take the first step towards better mental health!

PDLink volunteers wanted

Interested in mentoring and giving back within the Parkinson's community? PDLink is a peer-to-peer support program for people with PD and their carepartners. We are seeking volunteers who are carepartners, or have had PD for several years, who would like to mentor others about

Parkinson's. To learn more about the program, visit the [PDLink webpage](#). If interested, contact info@parkinson.bc.ca

Office Closure: July 3, Canada Day

Parkinson Society BC's (PSBC) office will be closed on Monday, July 3 for Canada Day. We will reopen on Tuesday, July 4. Please note that PSBC's regular office hours are 8:30am - 4:30pm, Monday through Friday, with the exception of statutory holidays.

DISCUSSION TOPIC: Advance Care Planning

Discussion Questions

1. Have you had a conversation with your loved ones or healthcare team about advance care planning? What are some strategies for initiating an advance care planning conversation?
2. What are some prominent issues to consider when advance care planning? How can you involve your healthcare team and loved ones in this process?
3. What role can you play in ensuring your care aligns with your values? What steps can you take to be an active agent in this process?

Due to the degenerative and chronic nature of Parkinson's disease (PD), most individuals with PD will require some level of support at some point in their journey with the disease. Navigating life with PD can bring about a heightened sense of uncertainty about the future, and patients often feel insufficiently informed about their diagnosis, and future disease involvement (Kurpershoek et al., 2021). While it can be difficult to predict how the disease will progress, one way to stay informed and take control is through advance care planning.

For some, advance care planning can bring a sense of comfort, ease, and increased engagement in day-to-day life. For others, it may bring worry and concern. The key is to listen to yourself and honour your preferences, knowing there is no one-size-fits-all approach to Parkinson's and planning for the future. Advance care planning (ACP) involves an ongoing dialogue that centers around the unique needs, wishes, and preferences of patients, particularly

when it comes to issues related to the disease and end-of-life care (Preparing for your Future, n.d.). Studies have shown that ACP can have a positive impact on quality of life (Kurpershoek et al., 2021). There are here are different approaches to advance care planning that can help you feel more empowered and prepared for the road ahead.

What are the benefits of planning advance?

Planning for the future is the best way to stay proactive in your care. ACP can greatly benefit individuals with Parkinson's disease by allowing them to better understand their disease, articulate their values and goals for care, and ensure their preferences are respected. ACP can also promote communication among patients, families, and healthcare providers, facilitating open discussions about the future, addressing concerns, and making informed decisions ("Joanne Taylor Answers Your Questions on Personal Planning," 2016).

As PD progresses, it may cause cognitive changes that can impact an individual's legal authority to make healthcare decisions. In that case, a loved one can be appointed power of attorney to make these decisions for them. It is important to make your loved ones aware of the type of care you wish to receive in the later stages of the disease, so they are prepared to advocate for you should they need to. By enabling patients to plan ahead and express their wishes, ACP can improve the quality of life for both patients and their families and ensure that care aligns with their goals and values, even as their condition changes over time.

Ultimately, ACP can empower individuals with PD to maintain control over their lives and care, deal with the uncertainty of the future, and provide peace of mind and confidence in the decisions made about their care. Remember, it is never too early to start planning, and by doing so, you can ensure that you and your loved ones are well-prepared for whatever may come ("Kathleen Yue Discusses Palliative Care for Parkinson's," 2019).

What issues should I consider in my planning?

To better understand your wishes, you might want to discuss certain questions or issues with your family, caregiver/partner, and healthcare team. Here are some questions to consider discussing with your Parkinson's healthcare team to help them assist you better:

- How does Parkinson's progress? What signs and symptoms should I be look out for?
- While Parkinson's medications can help my symptoms, what are their risks? For example, would you want to increase your PD medication, even if it results in increased dyskinesia?
- When would you recommend surgery? When would you not?
- If I have surgery for a non-Parkinson's related condition, how could Parkinson's affect my surgery and the care I receive in the hospital? How can I prepare for this?
- How could Parkinson's impact my thinking, memory, and mood (e.g., depression, anxiety, cognitive changes, etc.)? How might this be treated, and how could that change how I plan for the future?

In sharing this information with your family, you can say, "I know that Parkinson's may affect my ability to _____. If that happens, and I cannot speak for myself, this is what I would like you to..." Remember that this is an ongoing process, and you may change your mind about how you feel about things.

Carepartners and caregivers should also be included in advance care planning. Invite your carepartner to speak with your healthcare team to ask questions such as "What should carepartners keep in mind? How can I prepare for what could happen to my loved one with Parkinson's?"

How can I ensure my healthcare team is making the right decisions for me?

Being an active agent in your own care is crucial. While healthcare professionals have responsibilities of assessment, diagnosis, and treatment, they must also provide advice to inform their patients' decision-making. Your family doctor and neurologist are important sources of information about Parkinson's and its expected progression, including its impact on

reasoning, memory, and mood. By staying informed about your condition and care options, and voicing your opinions, preferences, and concerns, you have the power to decide how your healthcare team can best serve you. According to Walach and Loughlin (2018), “no amount of medical expertise can make [healthcare professionals] experts on which trade-offs are the right ones for [a] person to make in the context of [their] particular life goals.” This emphasizes the importance of being an active agent in your care by working alongside your healthcare team every step of the way.

In order to create a comprehensive and holistic care plan, your healthcare team needs to understand all the ways PD affects your life. This includes tracking your symptoms and experiences with PD and keeping your team informed of changes to your condition. Do not hesitate to share any of your concerns with the healthcare professionals you trust. Regardless of their specialty, doctors, nurses, and allied healthcare professionals (AHCPs) across BC are trained to take a person-first approach to their work. Your healthcare team can provide referrals and help you navigate specialized services, treatments and therapies, financial supports, and other options available to address your unique needs. Advocating for yourself may feel daunting, but it is an important part of helping healthcare professionals make informed decisions and tailor their approach to best suit your needs. You are your own best advocate! (“A Palliative Approach to Parkinson’s Care,” 2021)

Where do I start?

Starting your advance care planning can be intimidating because it involves considering a range of knowns and uncertainties. To make the process less overwhelming, consider following the three steps provided below as a guide. There is no particular order in which to complete them, and you do not have to do them all at once. The most important thing is to use the information in a way that is most beneficial for your personal planning.

Step 1: Identify your values

Begin by reflecting on what is most important to you. Values guide our decisions, attitudes, and actions. Ask yourself questions like: who matters to you most, when do

you feel most like yourself, and when are you most proud or happiest? It is important to acknowledge that our thoughts and desires may change over time, especially as we approach the end of our lives. Timestamping your values statement and communicating with loved ones about whether you want them to abide by that statement even if you lose your thinking and memory abilities can be useful. While having a written statement is crucial, conversations with loved ones are also necessary, as they can reveal emotions, nuances, and clarity that written words may not convey (Dolhun & Aamodt, 2022).

Step 2: Write down your plans and wishes

Written plans are called advance directives, which allow individuals to name someone they trust to make care and treatment decisions on their behalf if they become unable. This can include a healthcare power of attorney, a document that appoints someone to make medical and care decisions on the individual's behalf, and a living will, which describes what care and treatments the individual does or does not want near the end of life. Other legal documents that individuals may consider completing are a Do Not Resuscitate (DNR) order and Portable Medical Orders (POLST). When completing your advance directives, revisit your values and use them to guide your decisions. Advance directives are a back-up plan that protects individuals if life brings unexpected or unwanted changes. Having these written plans can provide clarity and a peace of mind for the individual with Parkinson's and their loved ones (Dolhun & Aamodt, 2022).

Step 3: Talk with loved ones

For many, talking to loved ones about later and end-of-life care is the toughest part of advance care planning. Before you approach these conversations, make a plan about whom you want to talk with and how to broach the topic. You can consider writing a letter to your loved ones and/or healthcare power of attorney to convey your values, beliefs, and wishes to help foster discussion. Social workers or palliative care providers are also equipped to help facilitate these discussions. It is important to note that these

conversations are ongoing, so do not try to cover everything in one conversation. This will minimize pressure and allow for time to reflect (Dolhun & Aamodt, 2022).

Although advance care planning can be a challenging and emotional process, it is ultimately empowering and can provide peace of mind for individuals with Parkinson's and their families. By taking the time to engage in advance care planning, individuals can ensure that their wishes are respected, and their healthcare team is informed. It is important to remember that advance care planning is an ongoing process and plans and wishes may change over time. Regularly revisiting and updating advance directives can ensure that they continue to accurately reflect personal values and preferences (Preparing for your Future, n.d.). With the support of healthcare professionals, loved ones, and the resources available, individuals with Parkinson's can take control of their healthcare decisions and live life on their own terms.

Additional Resources

- Advanced Care Planning | Connie Jorsvik [[view video](#)] [[view slides](#)]
- Legal Considerations: Plan Ahead & Long-term Healthcare Planning [[view video](#)]
- Healthcare Decision Making for Parkinson's [[view helpsheet](#)]

References

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