

SPECIAL NOTICE

In response to the global outbreak of COVID-19, Parkinson Society BC (PSBC) staff are working remotely until further notice. We will continue to offer programs and services in alternate formats. For the most up-to-date information, visit this web page: www.parkinson.bc.ca/coronavirus. If you have any questions, please contact us at info@parkinson.bc.ca.

UPCOMING EVENTS

- **Drumming for Parkinson's** | Wednesdays, March 16 – April 20
Learn more & register: <https://bit.ly/drummingforpdmarch>
- **SongShine with Joani** | Thursdays, March 17 – April 21
Learn more & register: <https://bit.ly/songshinemarch>
- **Virtual Gardening Group** | Every 2nd and 4th Thursday, March 10 – September 22
Learn more & register: <https://bit.ly/pdgardeninggroup>
- **Step by Step** | Begins in April
Learn more and register: www.parkinson.bc.ca/step-by-step
- **Bollywood Dance** | Tuesdays, April 5 – 26
Learn more & register: <https://bit.ly/bollywooddancepd>
- **Ask the Expert: Eye Health and Parkinson's** | Wednesday, April 6
Learn more & register: <https://bit.ly/eyehealthandpd>
- **April Challenger** | Thursdays, April 7 – 28
Learn more & register: <https://bit.ly/aprilchallenger22>
- **Annual General Meeting** | Saturday, April 23
Learn more & register: www.parkinson.bc.ca/agm-2021
- **Balance Exercise Series** | Tuesdays, May 3 – 31
Learn more & register: <https://bit.ly/balanceexercisepd>
- **Rock Steady Boxing with Doug Pickard** | Wednesdays, May 4 – 25
Learn more & register: <https://bit.ly/rocksteadypd22>
- **Global Symposium Series**
 - **Breakthrough Therapies for Parkinson's** | Wednesday, May 4
Learn more & register: <https://bit.ly/globalsymposium-breakthrough>
 - **Gyro-Kinetics for Parkinson's** | Wednesday, May 11
Learn more & register: <https://bit.ly/globalsymposium-gyrokinetics>

- **Personality & Behaviour Changes** | Friday, May 20
Learn more & register: <https://bit.ly/globalsymposium-personality>
 - **Communication & Swallow Workshop, Surrey** | Saturday, May 7
Learn more & register: www.parkinson.bc.ca/comm-swallow22
 - **Voice Aerobics®** | Thursdays, June 16 – 30
Learn more & register: <https://bit.ly/voiceaerobicspd>
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UPCOMING FUNDRAISING EVENTS

Champions for Parkinson's

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

We're 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 Alicia Wrobel at awrobel@parkinson.bc.ca or 1-800-668-3330 ext. 237

TIP JAR

The Tip Jar is where we share advice from Parkinson's community members. This month, we share advice on oral care.

- A community member from Vancouver found that chewing gum helps reduce dry mouth, as well as tension in the jaw that can result from dystonia. They recommend Dentyne Ice Intense, which they found to remain soft, chewy, and flavourful for over an hour.

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

April is Parkinson's Awareness Month

Every year, Parkinson Society British Columbia (PSBC) dedicates the month of April to raising awareness of the unique experiences of people with Parkinson's, and the needs of our community. Parkinson's Awareness Month is an opportunity to engage the public in expanding their understanding of Parkinson's, and the profound effects it has on the lives of over 15,000 British Columbians living with the disease.

This April, we want to spread the message that *Parkinson's is more than a tremor*. The disease can affect all aspects of one's life, and there is currently no known cure.

Our 2022 campaign highlights include:

- **Personal journeys** shared by people with Parkinson's, their families, and carepartners.
- The importance of **living well with Parkinson's**, through self-management, self-reliance, and self-advocacy.
- **Community ties and peer support** bringing together the Parkinson's community across British Columbia.

This April, we invite you to take part in our awareness campaign to help spread the message that Parkinson's is more than a tremor. Get involved through:

- **The Faces of PD campaign:** We are collecting photos from people with Parkinson's disease in BC to help draw attention to the diversity of the community. To learn more or to submit your photo, please visit www.parkinson.bc.ca/facesofpd.
- **Parkinson's Awareness Month postcards:** We are asking people to fill out postcards, reflecting on their personal experience with Parkinson's, in an effort to educate the public. These postcards may also be used in future communications to raise awareness. Submit your responses at <https://bit.ly/pdpostcardsubmission>, or visit <https://bit.ly/pdpostcardrequest> to request printed copies.
- **Upcoming social media and promotion:** Throughout the month of April, we will be sharing facts about Parkinson's disease, as well as wellness tips, on our social media

channels. Stay tuned to also see our video campaign, featuring personal journeys shared by people with Parkinson's, their families, and carepartners.

Register now! 2021 Annual General Meeting (AGM)

We invite you to join us for our Annual General Meeting on Saturday, April 23 at Bonsor Recreation Complex in Burnaby, BC. An option to attend virtually is also available.

This year's AGM will feature guest speaker Dr. Lara Boyd. Dr. Boyd is a neuroscientist and physical therapist who is currently a professor at the University of British Columbia. Her research efforts are leading to the development of new and effective therapeutic methods, some of which have applications for people with Parkinson's, including leveraging neuroplasticity. Neuroplasticity is the brain's ability to grow and "rewire" neural networks based on an individual's learning and life experiences. In this talk, Dr. Boyd will speak about the applications of neuroplasticity in managing Parkinson's symptoms.

Register today at www.parkinson.bc.ca/agm-2021. Please be advised this is a *member-only event*. Non-members interested in attending must pay the \$25 membership fee at www.parkinson.bc.ca/membership, or by contacting Susan Atkinson, *Donor & Member Services Coordinator*, at satkinson@parkinson.bc.ca or 1-800-668-3330 ext. 263.

Updated provincial health orders regarding in-person support group meetings

As per the updated COVID-19 restrictions, PSBC will resume in-person support groups for those who sign the indoor meeting agreement. Support groups may still choose to access our Zoom accounts if they prefer to remain virtual. For facilitator inquiries, please email Liz Janze, *Education & Support Services Coordinator*, at ljanze@parkinson.bc.ca or call 1-800-668-3330 ext. 228.

New! Healthcare Navigator role

The Society has hired a new part-time staff member who will be available to provide guidance for navigating the complexities of the healthcare system. You can access this assistance by

contacting by contacting us at info@parkinson.bc.ca. A staff member will work with you to assess your needs.

Support the expansion of the Deep Brain Stimulation (DBS) program in BC

In 2019, the BC Ministry of Health promised a second neurosurgeon to help reduce waitlist times for DBS surgeries. The waitlist to see Dr. Christopher Honey for initial DBS assessment is now up to four years. We need the BC Ministry of Health to follow through on their promise. TAKE ACTION and support our letter writing campaign today at www.parkinson.bc.ca/dba.

Volunteer as a community organizer for Parkinson SuperWalk

To make our largest fundraising event possible, we are seeking walk coordinators across five communities (Abbotsford, Comox Valley, Kamloops, Langley, and Prince George). Learn more and apply at www.parkinson.bc.ca/sworgrecruit.

Step by Step walk leaders needed

Step by Step is a 12-week walking program aimed at improving physical fitness to combat the symptoms of PD. To learn more or start a group in your community, please visit www.parkinson.bc.ca/stepbystepleaders.

Class action lawsuit: Gramoxone® (paraquat)

Gramoxone® is an herbicide used to control weeds and grasses with an active ingredient called paraquat. It is alleged that paraquat exposure is linked to Parkinson's disease (PD). Law firm Siskinds Desmeules has filed proposed class action lawsuits on behalf of all Canadians who have been diagnosed with PD after using and/or being exposed to Gramoxone®, since July 1, 1963. To learn more, visit www.parkinson.bc.ca/gramoxoneclassaction.

COVID-19 vaccination

Throughout 2022, COVID-19 vaccines will be made available to all Canadians. Read Parkinson Society BC's COVID-19 Vaccination Statement for more information about the vaccine – including how it works, how it will be distributed, and considerations for people with Parkinson's – at www.parkinson.bc.ca/covid-vaccine.

DISCUSSION TOPIC: Advanced Care Planning

Discussion Questions

1. What information do you have so far about advanced care planning?
2. What conversation starters have you found helpful when discussing advanced care planning with loved ones?
3. How have others responded to your advanced care plan? Did their responses surprise you in any way, and if so, how?

Legal Representatives and Agreements on your behalf

In the event you are hospitalized, it is important to have an appointed legal representative, as it will grant them the authority to speak on your behalf. An appointed legal representative will have the ability to pay your bills, retrieve your income tax information to help pay home care or facility fees, speak to companies such as ICBC, and make healthcare decisions or living arrangements if you are in a position where you are unable to. Without a legal representative, even a spouse or loved one can be limited in decisions and tasks they can do on your behalf. By appointing a legal representative and having these legal documents in place, it can ease the burden on others, providing you a say over matters affecting your quality-of-life and help avoid the involvement of government or the state in your private and personal affairs. Nidus.ca provides a variety of legal documents that suite the different types of legal document planning.

Types of Legal Document Planning

At Nidus.ca, you can find BC legislative documents available to appoint your legal representatives. Nidus Personal Planning Resource Centre and Registry breaks down planning into two categories:

1. **Personal planning** – *this planning is when your personal support can make arrangements due to an illness, injury, or disability while you are alive.*

Personal planning covers four areas of your life: healthcare, personal care, legal affairs, and financial affairs. The purpose of a personal plan is to have legal documents that give specific individuals the legal authority necessary to help you in case you are at end of life, incapacitated, or in need of other support. Nidus.ca, provides two different

paths/documents for personal planning. To access their forms and further information on these paths, see here: www.nidus.ca/types-of-planning. Advanced Care Planning falls under the area of Personal Planning.

2. **Estate planning** – *this planning is for making arrangements for after death.*

Nidus uses the term Estate Planning to refer to making arrangements for after death.

A Will is an essential document for estate planning. For further information on estate planning, see our helpsheet at: www.parkinson.bc.ca/media/176796/wills-and-estate-planning.pdf

It is important to discuss Advanced Care Planning (ACP), considered part of personal planning, with loved ones and healthcare providers while you are still capable to do so. These conversations will assist your legal Representative in understanding your future healthcare wishes. ACP is an umbrella term for conversations and documentation about your values, beliefs, and preferences for future care when you can't make your own decisions (Advanced Care Planning Canada, 2022).

It is recommended that you begin your Advanced Care Plan by having conversations about your beliefs, values, and wishes, followed by appointing Temporary Substitute Decision Makers (TDSM) or a representative for your healthcare decisions. Finally, be sure to safely store your Advanced Care Plan, so it is readily available for use. The organization Advance Care Planning Canada emphasizes ACP is important for all adults, no matter the person's state of health or age.

Advance Directives & Representation Agreements: What's the difference?

While Advance Directives and Representation Agreements are both used when another individual makes a healthcare decision on your behalf, and part of Advanced Care Planning, there are some notable differences to consider between the two.

Nidus explains that an **Advance Directive** is a legal document in BC that consists of specific written instructions to give or refuse your consent for certain healthcare matters. It must be made when you can understand the nature and effect of the healthcare treatment you are giving

or refusing consent for. An Advance Directive can be standalone, meaning it can be executed without anyone to give input on your behalf. For example, it could provide your consent for a specific healthcare instruction/treatment (ex. blood transfusions, feeding tubes, or life support). The instruction applies to the healthcare situation or circumstance at a time when you are incapable of providing consent. The instruction also must be clear enough that a healthcare provider can confidently act on it without consulting anyone else.

Having an Advance Directive on its own is not recommended as sometimes the wording does not meet the standard of BC legislation and/or the healthcare provider does not know the context for your treatment wishes. This can lead to limitations with the execution of an Advance Directive. Having a Representation Agreement in place will help provide context for your healthcare wishes, and reduce confusion for healthcare professionals around decisions of your care.

A **Representation Agreement** is a legal document in BC that covers healthcare *and* personal care matters. It is for authorizing one or more people to assist you with decisions or, if necessary, to act on your behalf (Nidus, 2022). It is recommended to have a trusted personal support as your legal representative as they will be able to carry out your prepared Advanced Care Plan. You appoint a legal representative by filling out a Representation Agreement form that can be found at www.nidus.ca/resources-ra. Your legal representative is an important part to have incorporated in your Advanced Care Plan, as they will represent your healthcare wishes if you are not able to speak for yourself.

Why you should have an Advanced Care Plan

Life events are unpredictable. Having an Advanced Care Plan will reduce stress placed on your loved ones and provide them with a guideline for making important decisions about your health when you are unable to (Advanced Care Planning Canada, 2022). It will also equip your legal representative, loved ones, and healthcare workers with the information they need to make the right decisions on your behalf.

Step 1: Conversation starters for Advanced Care Planning

To begin the Advanced Care Planning Process, Connie Jorsvik, an independent healthcare navigator & patient advocate, recommends answering the following questions either by yourself, with a caregiver, or a loved one:

- What makes your life worth living? (i.e. beliefs – what gives your life meaning?)
- What can or can't be sacrificed or comprised?
- What needs to be completed before death?
- What special faith-based or cultural preferences should be considered?
- Would you want life-saving measures? (i.e. breathing tubes, feeding tubes, life support)
- What do you or your loved ones value? (i.e. food, family dinners – what do you care about in life?)
- How do you feel about quality versus quantity of life?
- Where would you/they want to spend the last hours or days of life? (i.e. home, hospice, residential care)

Answering and discussing these questions provides an opportunity to have your loved ones understand your values, beliefs, and preferences for care.

Step 2: Assign a Legal Representative

After answering and discussing the conversations starters surrounding you believes and values, the next step is to appoint a trusted individual who will make your healthcare decisions on your behalf. Creating an Advanced Care Plan provides you the opportunity to decide who will be your Representative – the person who you entrust to make healthcare decisions for you.

You can file your Representation Agreement at registry@nidus.ca. It is also recommended that you provide paper copies to your Representative. If there is no legal Representative, as per BC Law, healthcare facilities will use a list of possible Temporary Substitute Decision Makers (TSDM) contacts in the following order: your spouse, your adult child, your parent, your sibling, a grandparent, a grandchild, anyone related to you by birth or adoption, a close friend, and a person immediately related by marriage (British Columbia, 2022). The BC government

recommends collecting all contact information from the above list and placing it in your ACP documents. This way, a TSDM can be easily contacted by healthcare professionals.

If you prefer not to have the healthcare system assign TSDM contacts, choose to name one person as your legal representative in a Representation Agreement. No lawyer is needed to name a person as your representative; however, it is recommended that you use the free Representation Agreement Forms from the nidus.ca website. A completed Representation Agreement Form can allow your representative to make healthcare decisions for you.

Whether you rely on a TSDM or naming a legal representative, the key is to collect their most up-to-date contact information, and have it listed in your Representation Agreement and your Advanced Care Plan document, so it may be easily found by your healthcare providers.

Step 3: Record your plan in a document

To assist your decision makers, there are a variety of ways to record your wishes in an Advanced Care Plan (ACP) document. There is the option to write down the contents of your ACP in your own documents, or by using ACP templates made available by different organizations.

The BC government provides an ACP template called *My Voice: Expressing My Wishes for Future Health Care* starting on page 27 of the document, found here: [My Voice](#)

Advanced Care Planning Canada provides another template option called *Speak Up: Start the Conversation About End-of-Life Care*. This template can be found on page 12 of the Speak Up document here: [Speak Up](#)

Additionally, Patient Pathways provides a template called *In Case of Medical Emergency (ICE)*. ICE is designed to speak for you when you are unable to speak for yourself or a loved one. This form gathers key information about you, your health, and your household. It makes the information readily available to first responders, paramedics, friends, and family (ICE Form Instructions). This can be found here: [In Case of Medical Emergency](#)

Once your Advanced Care Plan is written down in a document, it is recommended that you make multiple photocopies of the original document. It is best to place your ACP in a clear folder binder, or green sleeve, and to keep it on or beside your fridge. Your note on the fridge should state the location of the copies of the ACP and where the original copy can be found. Copies of these important documents should be handed out to your TDSM so they are prepared to have this information readily available for your healthcare providers.

Advanced Care Planning is important for all adults, no matter the person's state of their health or age. It is best to continue to review your plan at regular intervals and/or if anything changes related to the plan's contents.

Additional Resources

Wills & Estate Planning Helpsheets | www.parkinson.bc.ca/media/176796/wills-and-estate-planning.pdf

Nidus Representation Agreement Forms | www.nidus.ca/types-ra-forms

Government of BC Representation Agreement (Section 9) Form | www2.gov.bc.ca/assets/gov/health/managing-your-health/incapacity-planning/representation_agreement_s9.pdf

Public Guardian and Trustee of British Columbia | www.trustee.bc.ca/services/estate-and-personal-trust-services/Pages/default.aspx

Sources

Advance Care Planning Canada. (2022). *Speak up: Start the conversation about end-of-life care.*

www.advancecareplanning.ca/wpcontent/uploads/2020/06/acpworkbook_form_en.pdf

Government of British Columbia. (2022). *Advanced care planning.*

www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning

Government of British Columbia. (2022). *My voice expressing my wishes for future health care treatment*. www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf

Jorsvik, C. (2020). Advanced care planning for family caregivers and those they are caring for. www.youtube.com/watch?v=-2N4AsNT064

Nidus. Personal Planning Resource Centre and Registry. (2022). *Advanced Directive*. www.nidus.ca/advance-directive

Nidus. Personal Planning Resource Centre and Registry. (2022). *Types of Planning*. www.nidus.ca/types-of-planning

Nidus. Personal Planning Resource Centre and Registry. (2022). *Representation Agreement*. www.nidus.ca/resources-ra

Patient Pathways. (2020). *Advanced care planning for family caregivers and those they are caring for*. www.parkinson.bc.ca/media/237813/tofc-2-advance-care-planning-003.pdf