

UPCOMING EVENTS

Parkinson Society British Columbia endeavors to make attendance at events accessible to all who may benefit. The Society may be able to subsidize attendance fees for those who require financial assistance. Please contact Stacey at 1-800-668-3330 or sdawes@parkinson.bc.ca for more details.

COMMUNICATION AND SWALLOW WORKSHOP, CASTLEGAR

This full day workshop will focus on the communication and swallowing challenges faced by people with Parkinson's (PwP). The interactive and participatory format will allow attendees to practice treatment techniques and gain insight from a registered speech-language pathologist. This workshop is open to those already experiencing communication & swallowing challenges, as well as those who wish to be proactive in their treatment. A catered lunch will be provided.

To ensure the best learning experience, a minimum of 25 participants will be required 7 days prior to the event date. Please be advised that if these numbers are not met, we will be unable to proceed with the workshop and all registrants will receive a full refund.

Date: Friday, June 3, 2016
 Time: 9:00 am – 4:00 pm (registration opens at 8:30 am)
 Location: Sandman Hotel Castlegar | 1944 Columbia Ave, Castlegar ([map](#))
 Cost: Member \$40.00 | Member (Couple/Pair) \$70.00
 Non-Member \$50.00 | Non-Member (Couple/Pair) \$90.00
 Facilitator: Sherri K. Zelazny, MA RSLP
 Registration: Members: <http://bit.ly/1Utzm0D>
 Non-Members: <http://bit.ly/1Y4bdf5>

COMMUNITY TALKS WITH DR. ERIC AHLSSKOG

Professor of Neurology at the Mayo Medical School, and Chair of the Mayo Section of Movement Disorders, Mayo Clinic, Rochester, Minnesota, Dr. Eric Ahlskog is widely considered to be a leading authority on Parkinson's disease.

ABBOTSFORD

Topic: The Nuts and Bolts Approach to the Treatment of Parkinson's Disease
 Date: Thursday, June 9, 2016
 Time: 3:00 pm – 4:30 pm (registration opens at 2:30 pm)
 Location: Garden Park Tower | 101-2825 Clearbrook Road, Abbotsford ([map](#))
 Cost: Free
 Registration: <http://bit.ly/1UYOSBE>

VICTORIA

Topic: The Nuts and Bolts Approach to the Treatment of Parkinson's Disease
 Date: Friday, June 10, 2016
 Time: 2:00 pm – 3:30 pm (registration opens at 1:30 pm)
 Location: The Salvation Army Victoria Citadel | 4030 Douglas Street, Victoria ([map](#))
 Cost: Free
 Registration: <http://bit.ly/1UYOSBE>

ANNUAL GENERAL MEETING

On Saturday, June 11th, PSBC will hold its Annual General Meeting featuring keynote speaker Dr. J. Eric Ahlskog, PhD, MD of the Mayo Clinic, Minnesota. *This is a members only event.*

Date: Saturday, June 11, 2016
Time: 9:45 am – 12:00 pm (registration opens at 9:00 am)
Location: Vancouver Public Library, Alice MacKay Room | 350 West Georgia, Vancouver ([map](#))
Cost: Free for 2016 members
Registration: <http://bit.ly/1UYOSBE>

NIDUS - REPRESENTATION AGREEMENTS PRESENTATION

British Columbia has excellent legislation for personal planning to ensure people's wishes are carried out if they are incapable or cannot communicate. Representation Agreements are a legally enforceable document to cover health care as well as personal care decisions in the event of incapacity, at end-of-life and for other support needs. Individuals in Vancouver have an opportunity to attend an in-person presentation by Nidus.

Date: Friday, June 10, 2016
Time: 1:00 pm – 3:00 pm
Location: South Granville Seniors Centre | 1420 West 12th Ave., Vancouver ([map](#))
Cost: Free
Registration: No registration required

REGIONAL CONFERENCE, KELOWNA

Parkinson's is a journey with different stages and associated challenges. Our regional conferences provide attendees the opportunity to learn from experts and connect with others who have been affected by Parkinson's disease.

Date: Saturday, June 25, 2016
Time: 10:00 am – 4:00 pm (registration opens at 9:30 am)
Location: Ramada Kelowna Hotel & Conference Centre
2170 Harvey Ave., Kelowna ([map](#))
Cost: Member \$30.00 | Member (Couple/Pair) \$50.00
Non-Member \$40.00 | Non-Member (Couple/Pair) \$70.00
Registration: Members: <http://bit.ly/1Utzm0D>
Non-Members: <http://bit.ly/1Y4bdf5>

QUALITY CARE AT END OF LIFE: GOOD PROGRESS, COULD DO BETTER!

Join the UBC Division of Palliative Care and the Hsu & Hsieh Foundation in welcoming international speaker Professor Karen Forbes in the Arbutus Ballroom of the Holiday Inn Vancouver-Centre.

Date: Monday, June 27, 2016
Time: 6:00 pm – 7:30 pm
Location: Holiday Inn Vancouver-Centre
711 West Broadway, Vancouver ([map](#))
Cost: Free
Facilitator: Karen Forbes, MB, ChB, FRCP
Registration: <http://bit.ly/1TUP4N0>

COMMUNICATION AND SWALLOW WORKSHOP, PARKSVILLE

This full day workshop will focus on the communication and swallowing challenges faced by people with Parkinson's (PwP). The interactive and participatory format will allow attendees to practice treatment techniques and gain insight from a registered speech-language pathologist. This workshop is open to those already experiencing communication & swallowing challenges, as well as those who wish to be proactive in their treatment. A catered lunch will be provided.

To ensure the best learning experience, a minimum of 25 participants will be required 7 days prior to the event date. Please be advised that if these numbers are not met, we will be unable to proceed with the workshop and all registrants will receive a full refund.

Date: Friday, July 22, 2016
Time: 9:00 am – 4:00 pm (registration opens at 8:30 am)
Location: Parksville Community and Conference Centre | 132 Jensen Ave E, Parksville ([map](#))
Cost: Member \$40.00 | Member (Couple/Pair) \$70.00
Non-Member \$50.00 | Non-Member (Couple/Pair) \$90.00
Facilitator: Sherri K. Zelazny, MA RSLP
Registration: Members: <http://bit.ly/1Utzm0D>
Non-Members: <http://bit.ly/1Y4bdf5>

DRAWING FOR COGNITIVE EXERCISE WORKSHOP

This two-part workshop invites people with Parkinson's and their carepartners to explore their creativity through drawing. Robert Wilson, a PhD Candidate in the Interdisciplinary Studies Graduate Program at UBC, is looking at drawing as a "social cognitive exercise". After speaking with Dr. Jon Stoessl at the Pacific Parkinson Research Centre, who connected Wilson with the Society, Wilson hopes to guide participants through various drawing exercises aimed at benefiting their mind-body connection, as well as social engagement.

Dates: Thursday, August 11th 2016
Thursday, August 18th 2016
Time: 2:00 pm – 4:30 pm (doors open at 1:30pm)
Location: Adler University | 1090 West Georgia Street Vancouver ([map](#))
Capacity: 12 (min. of 6)
Cost: Free
Facilitator: Robert Wilson, PhD Candidate
Registration: <http://bit.ly/1UYOSBE>



DANCE FOR PD® INTRODUCTORY TRAINING AND ENRICHMENT WORKSHOP

Mark Morris Dance Group and Parkinson Society British Columbia, in association with Simon Fraser University's School for the Contemporary Arts, present a Dance for PD® Introductory Training and Enrichment Workshop.

This two-day workshop provides dance teachers, dancers, physical and occupational therapists and students, social workers, and allied health professionals with a comprehensive, inspiring introduction to the internationally-acclaimed Dance for PD® program.

Dates: Saturday, September 17 – Sunday, September 18, 2016
Time: 9:00 am – 6:00 pm
Location: Simon Fraser University, Vancouver Downtown Campus
Goldcorp Centre for the Arts, Woodward's Building
149 West Hastings Street, Vancouver ([map](#))
Capacity: 25
Fee: Tuition is US \$225 (PSBC-subsidized rate for BC residents is US \$150) | \$200 USD for Dance for PD® members. Enrollment is limited. For more information on the training course, please follow the link: <http://danceforparkinsons.org/training-workshops/training-courses>.

WORLD PARKINSON CONGRESS

Date: September 20 – September 23, 2016
Location: Oregon Convention Center | 777 NE Martin Luther King Jr Blvd, Portland, OR ([map](#))
Registration: <http://bit.ly/1OgnERG>

INTERNATIONAL SUPPORT GROUP LEADER RECEPTION

After a long day of learning at the World Parkinson Congress, join Parkinson's Resources of Oregon for a relaxing, social event with fellow support group leaders.

Dates: Wednesday, September 21, 2016
Time: 6:30 pm – 8:30 pm
Location: DoubleTree by Hilton Portland | Madison Ballroom
1000 Northeast Multnomah Street, Portland, OR ([map](#))
Fee: Free
Registration: <http://bit.ly/1Vhj8Yd>

For a listing of all upcoming education events, visit our [events calendar](#).

UPCOMING FUNDRAISING EVENTS

- 4 Peaks 4PD: Sunday, June 5, 2016 ([read more](#))
- Paddle for PD: begins Tuesday, June 7, 2016 ([read more](#))
- Sparwood Golf Tournament: Saturday, July 23, 2016 ([read more](#))
- Shake, Shake, Shake!: Friday, January 27, 2017 ([read more](#))

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

**put on your capes...
it's time to become a hero for parkinson's!**



register now

**help bring hope to those living with parkinson's.
over 20 walk locations across BC!**

<http://bit.ly/SuperWalkBC>

**EVERYDAY HEROES.
EXTRAORDINARY
HOPE.**

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FEATURED BOOKS FROM OUR LENDING LIBRARY

1. **Safe and Secure: Six steps to creating a good life for people with disabilities.** By Al Etmanski (2008). This book is primarily for families, friends and caregivers of people with disabilities. It offers a step by step guide to creating a plan for the future which provides for the safety, security and well-being of people with disabilities.
2. **Nursing Homes and Assisted Living: The family's guide to making decisions and getting good care.** By Peter S. Silin (2009). This second edition incorporates the new and baffling world of assisted living. It focuses on the psychological, emotional, and practical aspects of helping family members and seniors make a difficult transition.
3. **Parkinson's Disease and The Art of Moving.** By John Argue (2000). Mr. Argue has distilled information from his classes for Parkinson's patients into a comprehensive exercise program designed to help you improve flexibility, balance, gait, and communication.



View all resources available in our lending library: <http://www.parkinson.bc.ca/resources-services/library/>.

FEATURED TECHNOLOGY

1. **Predictable** is a text based Augmentative and Alternative Communication (AAC) app designed to give a voice to someone who is unable to use their own. It costs approximately \$219.99 (USD) from the App Store and is compatible with iPhone, iPad and iPod touch. ([more information about Predictable](#))

DANCE FOR PD® - COMMUNITY CLASS - VOLUNTEERS NEEDED!

PSBC is looking for individuals from the PD community to volunteer, attend and participate in a community demo class and discussion on Saturday, September 17 during the Dance for PD® training workshop. Anyone with PD is welcome. Please contact Caroline (cwiggins@parkinson.bc.ca or 1-800-668-3330) for more information

Date: Saturday, September 17
Time: 2:00pm – 3:30pm (Check-In begins at 1:30 pm)
Location: Simon Fraser University, Vancouver Downtown Campus Goldcorp Centre for the Arts
Woodward's Building | 149 West Hastings Street, Vancouver ([map](#))



If you wish to receive personal copies of GroupLink please connect with Caroline Wiggins, cwiggins@parkinson.bc.ca, and your name will be added to our GroupLink email distribution list.

PERSONAL PLANNING FOR THE WHOLE FAMILY: HEALTH CARE DECISION MAKING FOR PARKINSON'S



Most of us realize that we should make plans for our future, especially when it comes to our health care wishes. However, many of us avoid having these conversations and/or writing down our wishes; yet this is something every adult should do, ideally when we are healthy, not facing a health crisis, or in the hospital.

To assist you in this process, Parkinson Society British Columbia (PSBC) has prepared this document and a help sheet to help you, a person with Parkinson's or carepartner/family member/friend, to become more informed about health care planning as it relates to Parkinson's. Included are suggestions to guide you along the way. Please call us if you have any questions on this topic – we are here to help. For more information about advance care planning, please refer to the corresponding [help sheet](#).

Parkinson's will progress at a different rate for each person and it is hard to predict when your health will change. Therefore, it is important to learn about the treatments you may be offered in the future so you and your family have time to think through the risks and benefits and make informed choices. Many people who have done this kind of thinking ahead of time say that it gives them control over how they will cope with the impact of Parkinson's. As person with Parkinson's or a partner, having open conversations on how you would like to manage Parkinson's in both the best and worst case scenarios helps your family and friends to know your thoughts and ideas.

To plan or not to plan?

Ultimately, it is your choice. In British Columbia, you may choose to create a formal document to write down your health care wishes, such as an Advance Care Plan, Advance Directive and/or a Representation Agreement (these will be discussed in more detail throughout the document).

Alternatively, you may also decide to not write down your wishes, in which case it is especially important to regularly talk and review your wishes with your doctor(s) and family.

Advance care planning is:

- An ongoing process that includes personal reflection, talking with family members, friends, and substitute decision makers (those who will make decisions on your behalf), about what is important to you and what gives your life meaning.
- A process that includes talking with health care providers regarding the kind of medical treatment you may be offered in the future because of your illness. Throughout this process you might want to think about interventions you would or would not want to receive if you were unable to communicate. It will be important to share the reasons for your thoughts with your family and your doctors so they can ask you questions and clearly understand where you are coming from. It is very important to involve your doctors in these discussions so you can ask your questions and understand the risks and benefits of particular treatments.
- A process that addresses personal values and goals for living well.
- A verbal or written plan.

In British Columbia, there are a number of planning options. The BC Ministry of Health and other health care organizations suggest all Advance Care Planning processes include:

- Conversations with family or friends and health care providers about your wishes, beliefs and values.
- Writing down or recording your wishes, beliefs and values.
- Writing down the contact information for people who qualify to be your temporary substitute decision maker (this term is explained below).

Additional planning options include:

- **An Advance Directive** – a legal plan that allows you to write down and direct what type of health care treatments you wish to receive or not receive when you are unable to express your wishes.
- **A Representation Agreement** – a legal plan that allows you to appoint another adult to act on your behalf in making decisions if you are unable to do so. Representation Agreements can cover health care, personal decisions and/or routine financial matters.

It is also very important that you discuss with your doctor the type of health care and the terminology associated with treatments you may be offered in the future. This way, you can learn about different treatments before a health crisis and talk about what situations you may or may not want. Make your wishes, beliefs and values known, regardless of which type of document you choose.

Advance care planning IS NOT:

- **An Advance Care Plan is NOT a power of attorney.** In BC, if you give someone “power of attorney” they can only make decisions on your behalf regarding legal or financial matters, but not health care. Terminology and language in this area differ across Canada.
- **An Advance Care Plan is NOT the same thing as a No CPR Order** (known more commonly as a Do Not Resuscitate Order or DNR). Those are medical orders specifically about not attempting to restart your heart beat and breathing when they stop.

When should I start thinking about future health care decisions?

Now! The best time to think about these issues is before a crisis and certainly before you are in the hospital. Each one of us hopes that we will always be able to speak for ourselves, but we can never predict when we might need an Advance Care Plan or when our Advance Care Planning conversations will become vital for our family, friends and doctors. This is why we encourage every adult to make such a plan, whether they are people with Parkinson's, carepartners, or their family and friends.

Substitute Decision Maker or a Representative

- Think about who would be good substitute decision makers. Who knows you best, could honour your wishes and be able to communicate effectively in often emotional situations?
- You could identify someone specific, where only that person would make decisions on your behalf (called a Representative)? They must honour your wishes and instructions. It is therefore very important you have regular and on going talks with them about your wishes.

I have written an Advance Directive and/or Representation Agreement. Now what?

Keep the original. Make copies of the document(s) and distribute them to your doctor or nurse practitioner, the person who is your substitute decision maker, and other significant persons in your life. Bring your documents to all medical appointments, visits and admissions.

Where can I find more information about the Advance Care Planning process?

HealthLink BC has a variety of resources made available to those wanting more information about Advance Care Planning. Visit <http://www.healthlinkbc.ca/healthfeatures/advance-care-planning.html>.

The BC Centre for Palliative Care has commissioned the national Speak Up team to develop a new Advance Care Plan workbook for BC. The Speak Up BC online ACP workbook can be found here: www.speak-upinbc.ca.

The province of British Columbia is divided into five health authorities; each authority has their own information. See our help sheet, [Health Care Decision Making for Parkinson's](#), for health authority contact information.

For other areas, call [HealthLink BC](#) (8-1-1), give them your address and then ask them for the number of your local health unit.

There is generally no cost to writing an Advance Care Plan.

Wrapping it up

Planning in advance for health care decisions will not solve all the problems you will face with Parkinson's. However, by discussing your wishes for future care, you can decrease the stress faced by yourself as well as that of your family/significant others, who will be better prepared to make decisions on your behalf if necessary. You will have the opportunity to gain further control and input into your care and treatment – this is one way of taking charge and living well with Parkinson's!

PSBC gratefully acknowledges Fraser Health Authority, Cari Borenko Hoffmann, FHA Advance Care Planning Project Coordinator, and Sue Grant, BC Centre of Palliative Care, for their assistance with this project. Fraser Health does not warrant the accuracy or completeness of the information contained in [this document](#).