

# GROUPLINK 1

UPCOMING EVENTS | NEWS & ANNOUNCEMENTS | DISCUSSION TOPIC | CAREPARTNER'S CORNER DECEMBER 2017

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## UPCOMING EVENTS

Parkinson Society British Columbia (PSBC) endeavours 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 Caroline at [cwiggins@parkinson.bc.ca](mailto:cwiggins@parkinson.bc.ca) or 1-800-668-3330 for more details.**

### NEWLY DIAGNOSED WEBINAR SERIES: LEGAL AID FOR DUTY TO ACCOMMODATE & DISABILITY INSURANCE

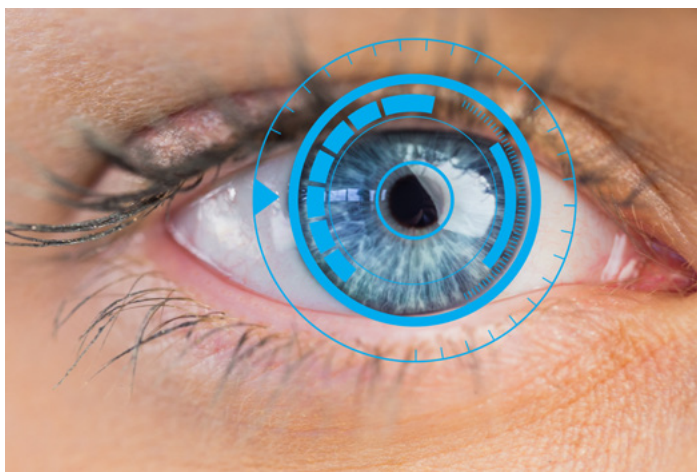
Join Eleni Kassaris, lawyer and partner at Blake, Cassels & Graydon LLP, who offers pro-bono legal services to the Society and PSBC members. Eleni will speak about employers' duty to accommodate and disability insurance.

Date: Tuesday, January 30, 2018  
Time: 10:00am – 11:00am  
Location: Via webinar. *A valid internet connection will be required to participate.*  
Cost: Free  
Registration: [www.parkinson.bc.ca/education-events/legal-aid](http://www.parkinson.bc.ca/education-events/legal-aid)

### NEWLY DIAGNOSED WEBINAR SERIES: NOW YOU SEE ME, NOW YOU DON'T – VISION ISSUES IN PARKINSON'S

This is the first time Jason Barton, Neuro-Ophthalmologist at St. Paul's Hospital and Professor of Medicine (Neurology) at the University of British Columbia, will join PSBC to discuss issues with vision in Parkinson's disease.

Date: Tuesday, February 20, 2018  
Time: 10:00am – 11:00am  
Location: Via webinar. *A valid internet connection will be required to participate.*  
Cost: Free  
Registration: Available soon



**TIME OUT FOR CAREPARTNERS WORKSHOP (NANAIMO)**

Parkinson Society British Columbia (PSBC) recognizes the efforts made by carepartners and caregivers every day. On February 24, 2018, we invite carepartners/caregivers to join us for a day of education, socialization and relaxation. Guest speakers will share experiences and strategies for coping with the complexities that arise as a result of Parkinson's disease (PD). Lunch and light refreshments will be provided.

**SPECIAL NOTICE:** An adjacent room will be available for people with Parkinson's (PwP) to partake in activities (e.g., light exercise, games, socializing), while their carepartner participates in discussions with other carepartners. We ask that PwP coming to this event respect this room divide, and refrain from attending sessions intended for carepartners. This room will be managed by volunteers who will provide companionship and light exercise activities. *The volunteers will not be medical professionals.*

Date: Saturday, February 24, 2018  
 Time: 10:00am – 3:30pm  
 Location: Vancouver Island Conference Centre  
 101 Gordon Street, Nanaimo ([map](#))  
 Cost: Member \$30 / Members (Pair) \$45  
 Non-member \$40 / Non-members (Pair) \$55  
 Registration: Available soon

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

# Champions FOR PARKINSON'S

- Shifting Gears for Parkinson's: March 13, 2017 – October 31, 2018 ([read more](#))
- Thoughts R Life Apparel: Online apparel sales that benefit PSBC, ongoing ([read more](#))
- Tea Parky: 35% from every sale on [TeaParky.com](#) will go to PSBC, ongoing. Special: Use promo code PSBC at check-

**WE'RE LOOKING FOR MORE CHAMPIONS TO HELP US IN 2018!**

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 Mirela at [mdzaferovic@parkinson.bc.ca](mailto:mdzaferovic@parkinson.bc.ca) or 1-800-668-3330.



Photo courtesy of [jjosuephotography](#)

## CONTRIBUTORS' CORNER

As the voice of British Columbians living with Parkinson's disease, PSBC strives to amplify voices within the Parkinson's community. We encourage British Columbians affected by Parkinson's to submit content they would like us to share online. Please note that content shared on our website is subject to a review process to ensure the information contained within is accurate and in line with our values and brand standards.

- Laura Wilson, [Vernon Parkinson's Warriors Fighting Back](#) (video)
- Dean Tweedle, [Walking the El Camino Trail](#) (travel blog)
- Laura Wilson, [Still no cure for Parkinson's](#) (letter)
- Mark Cope, [New Game New Rules](#) (short fiction)
- Lenora Klappe, [Robin Dunham](#) (article)



Dean and Glenni Tweedle on the El Camino Trail

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## TIP JAR

Have you been to a pool lately?

Swimming can be a great form of exercise! With the winter months fast approaching, swimming can be a nice indoor alternative for all you fitness keeners out there. Visit your local pool, community centre or aquatic centre to view their open swim schedules. Many centres even offer adult swimming classes and aquasize.

Bonus: Often, pool members also have access to a hot tub or sauna. What a great way to recharge, relax and socialize!

Do you have any tips or tricks that you would like to share with the PD 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 with Myriame at [mlepinyons@parkinson.bc.ca](mailto:mlepinyons@parkinson.bc.ca) or 1-800-668-3330.

### DISCUSSION QUESTIONS

1. What does it mean to be an advocate?
2. What would motivate you to become an advocate? Alternately, are there any hindrances or barriers to you becoming an advocate? If so, what are they?
3. What are some ways you have advocated for yourself or others in the past? (Hint: you've probably advocated more often than you think!)

Have you ever been involved in a public consultation on behalf of your family or a group? Have you defended a cause near and dear to your heart? Well, whether you realize it or not, you have acted as an advocate! The Merriam-Webster dictionary defines an advocate as:

- One who pleads the cause of another
- One who defends or maintains a cause or proposal
- One who supports or promotes the interests of a cause or group  
(Merriam-Webster Inc., 2017)

Parkinson Society British Columbia (PSBC) is proud to work with a strong team of Parkinson's advocates across BC and Canada. While PSBC can help identify the issues of greatest importance and help facilitate a concerted effort in working towards change, the reality is that the strongest voices are those of the individuals directly affected. In other words, there is no better voice than your own!

### PARKINSON'S ADVOCACY IN BC

Current health policies can be costly to both the province of BC as well as people affected by Parkinson's disease (PD). Despite the fact that PD is one of the most treatable neurological conditions, \$112 million was spent in the province of BC in 2012/2013 on direct care for Parkinson's patients (Ministry of Health, 201/2013). People with Parkinson's and their families are, in the meantime, faced with rising costs of medication as well as long wait times to see specialists. In light of recent advocacy success and feedback from the Parkinson's community, PSBC recently announced a revised Five Point Plan for Enhanced Support in October, 2017. The following five points will be areas of advocacy focus:

1. Add specialized staff to existing PD programs
2. Fund PD specific training for allied health professionals
3. Expand the Deep Brain Stimulation program
4. Expand medication coverage
5. Support for Carepartners  
(PSBC, 2017, October 13)

### DOES ADVOCACY WORK?

Thanks to a concerted effort of Advocacy Ambassadors and PSBC, we were able to encourage BC's Ministry of Health to approve public coverage of DUODOPA<sup>®</sup> under BC PharmaCare. DUODOPA<sup>®</sup> is a levodopa and carbidopa drug combination delivered in the form of a gel through an intestinal pump. On February 14, 2017, the Ministry of Health announced their intent to collaborate with the Pacific Parkinson's Research Centre (PPRC) to identify and prioritize patients for coverage of DUODOPA<sup>®</sup>. This was a big win for the BC Parkinson's community!

Despite this win, there is more progress to be made. For example, Deep Brain Stimulation (DBS) is a surgery that may be an option for a small number of BC patients with Parkinson's disease. Due to current funding limitations, candidates for DBS often wait for a number of years before receiving this treatment, prolonging symptoms and potentially leading to disease progression. Expanding the DBS program is now a major focus of the current advocacy strategy.

If you would like to provide feedback or become an Advocacy Ambassador, please contact Jean Blake, Chief Executive Officer, at [jblake@parkinson.bc.ca](mailto:jblake@parkinson.bc.ca) or 1-800-668-3330.

**WHAT CAN YOU DO RIGHT NOW?**

Ensure that you've contacted Jean Blake (contact information located on page 4) and expressed interest in becoming an Advocacy Ambassador. Jean can then include you on her regular updates and callouts.

**TAKE ADVANTAGE OF THE TOOLS AND RESOURCES AVAILABLE TO YOU:**

- Did you know that PSBC members get a free Aware in Care kit? A kit is designed to protect, prepare and empower people with Parkinson's and their carepartners before, during and after a hospital visit. Each kit includes a bag, a hospital action plan, a PD ID bracelet, a medical alert card and more useful tools. To learn more about the Aware in Care kit, visit [www.parkinson.bc.ca/aware-in-care](http://www.parkinson.bc.ca/aware-in-care).
- Read the full Five Point Plan for Enhanced Support for Parkinson's disease in BC at [bit.ly/Advocacy5Points](http://bit.ly/Advocacy5Points)



YOUR DOCTOR WANTS YOU TO  
GET YOUR MEDICATIONS ON TIME.

IN THE HOSPITAL  
**3** <sup>OUT</sup>  
**4**  
PEOPLE WITH  
PARKINSON'S DON'T.

**GET AWARE IN CARE.**

 MAKE IN CARE  
PARKINSON  
FOUNDATION

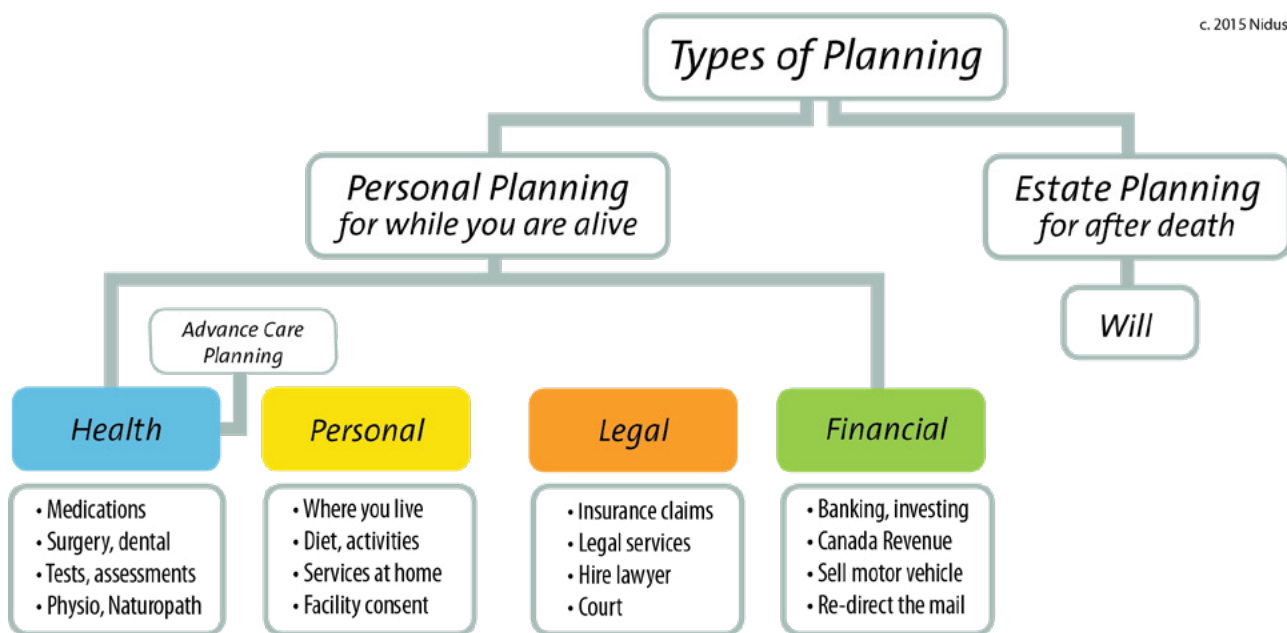
Parkinson Society  
British Columbia

The graphic features a smiling male doctor in a white coat and glasses, with a stethoscope around his neck, looking towards a smiling female patient. The background is a solid blue color. The text is white and blue, with the number '3' being significantly larger than the '4'.

In many ways, being a carepartner also means being an advocate. Not only are you working, volunteering, exercising, cooking, shopping, etc., but you may be representing your loved one with Parkinson's. This could mean speaking up for them at restaurants, doctor appointments or during family team meetings at the care facility; because of this, you may have inadvertently become a health advocate. In such instances, you are representing your loved one in accordance with their values and wishes of personal and health care. Have you taken the next step: planning for future care through personal planning?

Personal planning involves four aspects of life: health, personal, legal and financial. Personal planning addresses issues that arise when an individual is alive, whereas estate planning deals with matters that arise after death, such as settling an estate.

c. 2015 Nidus



In personal planning, you should prepare a Representation Agreement (RA). An RA is a legally enforceable document and the only way to authorize someone – referred to as a Representative – to assist or to act on another person’s behalf for health care and personal care matters (RA9). Some might also designate a RA to cover routine financial affairs and legal matters (RA7 F+L).

A Representative has legal authority to help a loved one manage their affairs and carry out wishes if they need temporary or ongoing assistance due to illness, injury or disability. Becoming your loved one’s Representative is straight forward, as long as the appropriate documentation is provided.

A Representation Agreement Section 9 (RA9) is for individuals who are considered mentally capable of understanding. This document will cover health and personal care matters. For additional, comprehensive financial plans, individuals can make an Enduring Power of Attorney. For more details about completing the forms, visit [www.nidus.ca/PDFs/Nidus\\_Form\\_RA9.pdf](http://www.nidus.ca/PDFs/Nidus_Form_RA9.pdf).

Some adults find that they are in a position where they need assistance in making important choices, but their mental capability is now in question. In this case, they may not be capable of completing their own documentation. Under these circumstances, a family member or carepartner will need to help them prepare a Representation Agreement Section 7 (RA7). A RA7 can cover routine finances as well as minor and major health care and personal care. For more information about this document, visit [www.nidus.ca/PDFs/Nidus\\_Form\\_RA7\\_all.pdf](http://www.nidus.ca/PDFs/Nidus_Form_RA7_all.pdf).

## WHAT STEPS CAN I TAKE TOWARDS PERSONAL PLANNING?

1. Determine which personal planning path applies to you and your loved one – (RA9) or (RA7). It is important to prepare the document(s) that fit(s) your path. If you need more information as to which path to take, read [www.nidus.ca/PDFs/Nidus\\_Info\\_LetsPlan.pdf](http://www.nidus.ca/PDFs/Nidus_Info_LetsPlan.pdf).
2. Identify your support system. Do you have friends or family members that you trust to respect your wishes?
3. Discuss roles and duties related to your planning documents with your support system.
4. Create the relevant legal documents.
5. You may choose to register your completed documents with the Personal Planning Registry ([www.nidus.ca/?page\\_id=238](http://www.nidus.ca/?page_id=238)). This is a secure online service for storing your information and decisions online, while ensuring that they will become available to those who need access down the road.
6. Distribute your documents to the relevant individuals or groups – and ensure that both you and others keep them safe!
7. Review your documents and discuss your current wishes with those you named at least once a year.

## QUICK TIPS

- Personal planning is for everyone! Both you and your loved one should consider values and future plans, and then complete the necessary documentation.
- Do not put wording in your Representation Agreement or Enduring Power of Attorney to say that it will come into effect later. The documents may be needed at various times. They need to be in effect when signed.
- Be careful – often, although it may be helpful to provide specific instructions or wishes for your family, this information does not need to be included in the legal document itself. You can write any additional information on a separate page, which can be updated as your condition progresses.
- Have ongoing conversations – Nidus provides the Values and Beliefs Discussion Guide as a resource. Go to [www.nidus.ca](http://www.nidus.ca) – click Get Help, then Discussion Tools to access this guide.
- Completing the legal documents listed on the Nidus website ([www.nidus.ca](http://www.nidus.ca)) will ensure that you and your loved one are prepared.

The information in this Carepartner's Corner has been adapted from materials provided by Nidus.

## Sources

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