SEPTEMBER 2016

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, PRINCE GEORGE

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: Saturday, October 15, 2016

9:00am - 4:00pm (registration opens at 8:30 am) Time: Spruce Capital Senior's Recreation Centre Location:

3701 Rainbow Drive, Prince George (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/PSBCMemReg

Non-Members: http://bit.ly/PSBCNonMemReg

REGIONAL CONFERENCES

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.

KAMLOOPS

Date: Saturday, October 29, 2016

Time: 10:00am - 4:00pm (registration opens at 9:30 am) Thompson Rivers University - Mountain Room Location:

900 McGill Rd, Kamloops BC (map)

Member \$30.00 | Member (Couple/Pair) \$50.00 Cost:

Non-Member \$40.00 | Non-Member (Couple/Pair) \$70.00

Registration: Members: http://bit.ly/PSBCMemReg

Non-Members: http://bit.ly/PSBCNonMemReg

VICTORIA

Date: Saturday, November 5, 2016

Time: 10:00am - 4:00pm (registration opens at 9:30 am)

Sandman Hotel Victoria - Orchid Room Location:

2852 Douglas Street, Victoria (map)

Member \$30.00 | Member (Couple/Pair) \$50.00 Cost:

Non-Member \$40.00 | Non-Member (Couple/Pair) \$70.00

Registration: Members: http://bit.ly/PSBCMemReg

Non-Members: http://bit.ly/PSBCNonMemReg

UPCOMING EVENTS

WORLD PARKINSON CONGRESS

Date: September 20 – September 23, 2016

Location: Oregon Convention Center

777 NE Martin Luther King Jr Blvd, Portland, Oregon (map)

Registration: http://bit.ly/10gnERG

WORLD PARKINSON CONGRESS SOCIAL

After a long day of learning at the World Parkinson Congress, join PSBC for a relaxing, social event with fellow British Columbians.

Date: Wednesday, September 21, 2016

Time: 5:00pm - 7:00pm

Location: Courtyard by Marriot Portland Downtown Convention Centre

435 NE Wasco St, Portland, Oregon (map)

Cost: Free



For a listing of all upcoming education events, visit our events calendar.

UPCOMING FUNDRAISING EVENTS

- Kitsch N Sync: Saturday, October 15, 2016 (read more)
- Shake, Shake!: Friday, January 27, 2017 (read more)
- Cotswolds Walking Holiday: August 31 September 8, 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.

PARKINSON SUPERWALK

Are you ready to become a hero for Parkinson's?

Register as an individual or team up with your friends, family or coworkers! Join us for Parkinson Society British Columbia's largest fundraising event of the year, Parkinson SuperWalk. In September, incredible British Columbians in over 20 communities throughout the province will walk together to help give hope to the 13,300 (2014/2015) people in BC living with Parkinson's.

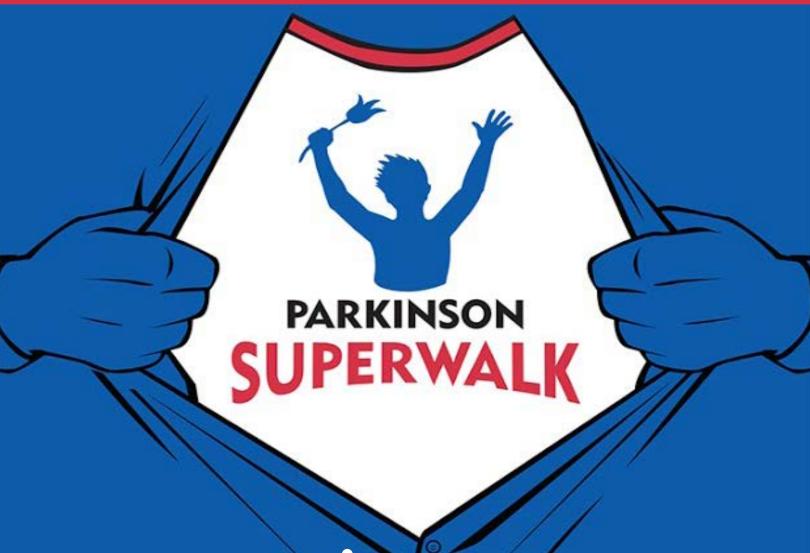
Funds raised in BC through this event help to provide valuable support services and education offered by Parkinson Society British Columbia in the province, as well as fund research efforts. Register now!

VOLUNTEER AT THE VANCOUVER OR SURREY SUPERWALK!

We are currently recruiting volunteers for SuperWalk in Vancouver and Surrey on Sunday, September 11th. For more information on the volunteer positions available, please contact Mirela Dzaferovic at mdzaferovic@parkinson.bc.ca or 1-800-668-3330.



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!

EVERYDAY HEROES. EXTRAORDINARY HOPE.

NATIONAL PARKINSON FOUNDATION'S CAREGIVER SUMMIT

This daylong event will bring together caregivers from all over the world to share experiences and everyday strategies for coping with the complex problems that arise as a result of Parkinson's disease.

If you cannot attend in person, general sessions of the Caregiver Summit will be broadcast live. You will have the opportunity to ask questions of the presenters just like the people in the room.

Date: Monday, September 19, 2016

Time: 9:00am to 4:00pm Location: DoubleTree by Hilton

1000 NE Multnoma St, Portland, Oregon (map)

For more information, please visit: http://www.parkinson.org/Caregiver-Summit

NOMINATE A HERO FOR THE CANADA CARES \$10,000 ONE WISH AWARD

Canada Cares gives a \$10,000 One Wish Award and National, Regional, Community and Employer Awards to incredible Canadians who make it their life's work to care. To find out more, and to nominate someone, visit http://www.canadacares.org. Nominations close September 30, 2016.

VOLUNTEER OPPORTUNITY: TRI-CITIES CAREPARTNER SUPPORT GROUP FACILITATOR

PSBC is actively recruiting a volunteer Support Group Facilitator for the Tri-Cities Carepartner Support Group. This support group is for individuals who care for someone with Parkinson's. Those involved meet on the second Thursday of each month between 10:00am and 12:00pm at 750 Delestre Ave. in Coguitlam.

The responsibilities of Support Group Facilitators include:

- Working to create an environment that is safe and respectful, and where participants feel comfortable sharing their experiences, insight and knowledge with others.
- Assisting with the delivery of information, education and resources for people with Parkinson's and their carepartners/families.

For more information, please contact Stacey Dawes at sdawes@parkinson.bc.ca or 1-800-668-3330.

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 at cwiggins@parkinson.bc.ca or 1-800-668-3330 for more information.

Date: Saturday, September 17, 2016

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)

North Shore SongShine Group

Date: Tuesdays, September 27 - November 29, 2016

Time: 12:45pm to 1:45pm

Location: North Shore Stroke Recovery Centre (NSSRC)

225 East 2nd St, North Vancouver (map)

Cost: \$12 per session for non-members of the NSSRC, and members would pay less as they've already paid a

membership fee.

Contact: Joani Bye, joanibye@icloud.com or 604-202-9784; Penelope Bacsfalvi, slp@nssrc.org

Delta SongShine Group

Date: Thursdays, September 29 - December 1, 2016

Time: 1:00pm to 2:15pm

Location: Kennedy Seniors Recreation Centre (map)

Cost: \$10

Contact: Kennedy Seniors Recreation Centre, 604-594-2717

NEW! Support Group - Langley Young Onset PD (YOPD) & Young at Heart

Date: 3rd Sunday of each month Time: 10:00am - 12:00pm

Location: Willoughby Community Centre at Langley Events Centre

7888 200 St, Langley (map)

Please find an up to date list of all of the Parkinson's specific Community Exercise programs across the province, there may be one near you! http://www.parkinson.bc.ca/exercise

Note: Any listing in the aforementioned documentation should not be considered an endorsement of the third party event(s). As such, the Society cannote be held responsible or liable for any loss or damage suffered as a result of participation.



SUBSCRIBE TO GROUPLINK!

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.

DISCUSSION TOPIC 7

PARKINSON'S AND DEMENTIA



Talking about dementia can be frightening. It is very important to remember that not everybody with PD will experience cognitive changes. And, while over half of people diagnosed with Parkinson's do experience a degree of cognitive decline, not all go on to develop dementia.

As with all symptoms of PD, everyone is different.

Parkinson's disease (PD) dementia is a condition that some people can experience after living with PD for some time. The purpose of this article is to provide a brief overview of cognitive changes and dementia relating to PD in order to distinguish it from Lewy Body Dementia and Alzheimer's disease. It is often difficult to accurately diagnosis the precise form of dementia a person may have. Therefore, this information is intended to provide a broad overview only.

What is cognitive decline as it relates to Parkinsons? Cognitive decline includes difficulties with attention, task completion, decision-making, problem solving, memory and word-finding. These symptoms can be very frustrating and annoying but may not, in the early stages, have a serious impact on one's daily life.

What is dementia?

Dementia is described as a serious decline in the cognitive challenges listed above, to the point where they have a significant impact on functioning and daily life. Dementia represents a dramatic change in one's ability to live life and the symptoms are often the most difficult for caregivers and families to cope with.

Symptoms: PD dementia

Parkinson's dementia can potentially have a greater impact on social and occupational functioning compared with Alzheimer's disease due to the combination of motor AND cognitive impairments. Development of dementia in Parkinson's represents progression of the disease, usually after quite a number of years of motor impairment.

Symptoms of Parkinson's dementia include:

- Forgetfulness
- Slow thought processes, difficulty concentrating and fluctuating attention
- Difficulty with word-finding
- · Difficulty with decisions, planning and problem solving
- Sleep disturbance
- Hallucinations
- Depression

What is Lewy Body Dementia?

This is a type of dementia associated with Parkinson's that is characterized by the presence in the brain of what are known as Lewy Bodies. Discovered by Dr. Friedrich Lewy, Lewy Bodies are abnormal clumps of protein found in the brains of people with Lewy Body Dementia and people with Parkinson's.

Symptoms: Lewy Body Dementia

The diagnosis of Lewy Body Dementia can include:

- Memory problems
- Slow thought processes, difficulty concentrating and fluctuating attention
- Sleep disturbances
- Depression
- Hallucinations
- · Muscle rigidity and/or other motor symptoms of PD
- Fluctuations in thinking causing confusion
- Symptoms of Parkinson's, eq. tremor, stiffness and slowness of movement

DISCUSSION TOPIC 8

What is Alzheimer's Disease?

Alzheimer's Disease is a form of dementia relating to the development in the brain of substances known as "plaques", which are toxic to neurons, and "tangles," which interfere with vital processes, eventually choking off the living cells.

Symptoms: Alzheimer's Disease

Symptoms of Alzheimer's can include:

- Memory loss that disrupts daily life
- Difficulty planning and finishing tasks
- · Confusion, disorientation
- · Apathy and depression
- · Behaviour changes
- Difficulty speaking

How are the various forms of dementia treated?

At the present time there is no medication approved specifically for Parkinson's dementia or Lewy Body Dementia but certain medications used in the treatment of Alzheimer's have proven helpful for some people. Medications that may be considered by your physician include:

- Cholinesterase inhibitors, normally prescribed for Alzheimer's disease, may help with PD dementia and Lewy Body Dementia
- Antidepressants can be helpful in alleviating the depression often associated with Parkinson's dementia and Lewy Body Dementia.

It is important to bring an accurate list of symptoms of cognitive decline and/or dementia with you to your neurologist and, if at all possible, a care partner, friend or family member should be present during your appointment.

For more information:

Lewy Body Dementia Association (http://www.lbda.org/)

Alzheimer Society British Columbia (http://www.alzheimerbc.org/)

Mind, Mood and Memory, National Parkinson Foundation (http://www.parkinson.org/sites/default/files/Mind_Mood_Memory.pdf)

COMMUNICATING EFFECTIVELY WITH A PERSON WITH PARKINSON'S WHO HAS COGNITIVE IMPAIRMENTS



Communicating with anyone suffering from cognitive impairments, like dementia or cognitive decline, can be difficult. It can be even more challenging if the person with cognitive impairment also has Parkinson's disease (PD). In the later stages of PD, the combination of cognitive changes together with physical symptoms, such as lack of facial expression, diminished voice quality and limited body language, can make it especially difficult to connect and have a conversation with the person you care about.

While about 50% of people with PD will experience some cognitive decline as the disease advances, only approximately 30% of those with cognitive decline will go on to develop dementia in the later stages.

As with all symptoms of PD, everyone is different.

The following are some of the symptoms of advanced cognitive decline and/or dementia that can get in the way of interactions and communications with the person you care about:

- Difficulty concentrating
- Difficulty with planning and sequencing tasks
- Changes in perception
- Altered judgment
- · Slowness of thought and in expressing thoughts
- Problems with word-finding
- · Difficulty following conversations in large groups
- Difficulty understanding the emotional meaning of a conversation
- · Difficulty changing topics quickly, or losing 'train of thought' when talking
- Visuospatial difficulties (such as conceptualizing things in 3D)
- Forgetfulness and difficulty with retrieval of learned information
- Behavioural changes (such as aggression)
- · Language deficits (including finding words, articulation, volume and tone)

The skill that is often impaired first is the ability to think of the right word. People may struggle to put thoughts together and require more time to organize and communicate their thoughts.

Another skill that may be impaired early on is the ability to understand complex sentences and concepts. A person's contributions to conversations are often affected. The person may not try to explain original thoughts or insights and their breadth of topics for conversation may be narrower. As PD advances, these communication skills may begin to worsen.

So, how do you enhance your communication with a person with PD dementia?

Sometimes the best thing you can do is to just listen and show that you care.

Speak slowly, clearly and carefully

Speak to the person as an adult, but make a conscious effort to speak slowly and clearly. Use simple words and short sentences and say exactly what you mean. Minimize implied messages to make a point. For example, rather than saying 'it's raining again!' Say: 'It's raining so we can't go out for a walk.' Use real names instead of pronouns, to remind the person who you are speaking about. Also be careful with teasing or sarcasm, which can be easily misunderstood.

Ask closed questions

Closed-ended questions which elicit a "yes", "no", "maybe" or "I don't know" answer may be more effective than open-ended questions. For example, "Are you ok?" may be more effective than "How are you doing?"

Be aware of non-verbal communication

This goes both ways. Be aware of tone of voice and other forms of non-verbal communication, such as facial expression and body language. Do not however, rely on non-verbal communication to clarify the meaning of your message, as the person you are speaking with may not intuitively understand what your tone of voice, body language or facial expression means. Always verbalize how you are feeling and what you are thinking.

Show and talk

Use actions and gestures as well as words. For example, if you are going out for a walk, motion towards the door or bring the person's coat to illustrate what you mean.

Repeat important information

If you are uncertain that your message was understood, repeat it using different words. Also try summarizing segments of your conversation. If the person seems to have lost their train of thought, clarify what was being discussed (e.g., "we were talking about going out this evening. Would you still like to go out?").

CAREPARTNER'S CORNER

Encourage exchange

Make conversations a two-way process that engages the person. Avoid interrupting or answering questions directed at the person with PD, which may discourage them from communicating. Be patient. Assist them with finding the right words if they seem to be struggling.

Take time

PD may have slowed the person's ability to respond or react. Be positive and reassuring and give ample time for the person to respond. For social situations, come up with and agree upon some cues that you can give the person with PD so that they can participate in conversation.

Examples include 'fillers' (e.g., "John and I were talking about this the other day and he had the most interesting point, John ..."). Using fillers and other cues allows the person with PD enough time to process the conversation and plan their contribution.

Choose the best time to communicate

"Off" periods (when medication is not managing symptoms effectively), excessive day-time sleepiness, and periods of anxiety and depression may not allow for effective communication.

Set the stage

It can be difficult to communicate if there are distractions. Turn off the TV or radio and avoid multi-tasking so you can focus on having a conversation. Also, simplify the environment by, for example, finding a secluded corner to have an intimate conversation. Avoid large groups when possible and encourage conversations with one or two people at a time.

Keep to a regular routine

Maintaining a regular routine can help reduce confusion and stress for the person having cognitive impairments. Keeping to a consistent schedule for meals, visits and surroundings can provide more opportunities for a comfortable conversation.

Get the person's attention

Some ways of getting the person's attention include slowly approaching and facing the person, gently touching a hand or arm then waiting until he or she seems ready to listen. Making eye contact is very important and appropriate physical contact may be reassuring.

Hearing or vision problems

Make sure that you and the person you care about have had vision and hearing tests and are wearing the appropriate hearing aid or glasses if required.

View communication as a partnership

Be mindful that you both have a role in making communication successful. Avoid over-correcting errors made by the person with PD. Also, be aware that learning to recognize disease-related changes and to communicate differently takes time. Be patient with yourself and with the person you care about.

Remember, the person you care about has the same feelings and needs as they had before developing cognitive impairment, such as dementia.