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UPCOMING EVENTS

Regional Conference - Vancouver

Thursday, June 11, 2015 - 10:00am - 4:00pm

Italian Cultural Centre | 3075 Slocan Street, Vancouver

This June, join us in Vancouver to learn from leading experts in the field – helping you to live well at every stage. Speakers include: Dr. Claire Hinnell, Matthew Sacheli, Erin Reeds and Joanne Taylor.

Registration available at: www.parkinson.bc.ca/vancouver-conference

Voice & Swallow Seminar - Burnaby

Wednesday, June 17, 2015 & Wednesday, June 24, 2015 - 10:00am - 3:00pm

Accent Inns | 3777 Henning Drive, Burnaby

Facilitated by Sherri Zelazny, Registered Speech Language Pathologist and Certified LSVT Practitioner, this two-day seminar will focus on the voice and swallowing challenges faced by people living with Parkinson's. It will be an interactive and participatory format, and all levels of voice and swallow disorder are welcome, including those who currently do not experience voice or swallow symptoms but wish to be proactive with their treatment.

Registration available at: www.parkinson.bc.ca/Burnaby-Voice-and-Swallow

PWR!Instructor Training & Certification Workshop

Wednesday, September 23, 2015 & Thursday, September 24, 2015

Fortius Sport & Health | 3713 Kensington Avenue, Burnaby

This course is suitable for professionals holding a current nationally or provincially recognized certification including fitness trainers, group fitness instructors, yoga instructors, pilates instructors, dance instructors and individuals holding a minimum 2-year Associates Degree in health, exercise science or recreation. Physical therapists, physical therapist assistants, occupational therapists and occupational therapist assistants are also welcome to attend.

Registration available at: www.parkinson.bc.ca/pwrinstructor-training

PWR!Therapist Workshop

Saturday, September 26, 2015 & Sunday, September 27, 2015

G.F. Strong Rehabilitation Centre | 4255 Laurel Street, Vancouver

This course provides the framework for how to implement neuroplasticity-principled techniques in a 1 on 1 rehab setting. It is targeted at physical/occupational therapists and physical/occupational therapist assistants.

Registration available at: www.parkinson.bc.ca/pwrtherapist-workshop

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

NEWS

Update on Counselling Services

In April 2015 we announced that the Society now provided free, short-term, confidential counselling services. Our Registered Clinical Counsellor, Courtney Hanna, will now be *available on Fridays* for those living with Parkinson's and their loved ones. For more information, please call 604 662 3240, 1 800 668 3330 or email counselling@parkinson.bc.ca.

Research Subjects Needed: Neural Control of Posture & Movement Laboratory

Title: A novel approach to studying postural instability in Parkinson's disease

Purpose: The study will compare balance ability during quiet standing and while controlling a balance simulator while lying down in individuals with Parkinson's disease and healthy older and young adults.

The Neural Control of Posture and Movement Laboratory at UBC is looking for healthy older adults and patients with Parkinson's disease (55-85 years old), and healthy young adults (19-40 years old). If you have any other causes of balance or cognitive impairment or proprioceptive loss (loss of normal sensation of movement) in your feet or lower leg, considerable tremor or uncontrollable movements/postures, or have had any neurosurgical procedures for Parkinson's disease such as deep brain stimulation, or brain surgery you should not participate.

You must be fluent in English to participate in the study.

Time: Subjects will be asked to commit 1.5 hours

Compensation: A monetary compensation will be given at the completion of the experiment.

Contact: Mark Carpenter | mark.carpenter@ubc.ca | 604 882 8614

Location: Neural Control of Posture and Movement Laboratory
University of British Columbia (UBC)



NEW RESOURCES

We're always adding new tools and resources to our lending library. Our library consists of books and DVD's that can be borrowed from our Vancouver office if you are a member of the Society. Check out our latest additions!

For more information on how to borrow resources, please contact Myriame Lepine Lyons at 604 662 3240, 1 800 668 3330 or mlepinelyons@parkinson.bc.ca.

Shaky Hands - A Kid's Guide To Parkinson's Disease. Dr. Sonia Mathur, et. al.

Millions of people worldwide have Parkinson's disease. But it doesn't just affect those with the diagnosis, it impacts whole family units, including our children. When a child learns that a loved one has Parkinson's disease, it can be a frightening time for them because they don't understand what a diagnosis such as this actually means. This book hopes to address the questions that may naturally arise. What is Parkinson's disease? How does it feel to have Parkinson's? How is it treated? How do I deal with all the feelings I have as I see the one I love change? What can I do to help? Reading the information contained and encouraging open dialogue, will help children cope with a loved one's journey with Parkinson's.

My Grandpa's Shaky Hands. Dr. Sonia Mathur, & James Walker.

Parkinson's disease affects millions of people worldwide. It is a disease that challenges every aspect of a person's life including relationships with family, friends and particularly those most vulnerable, the children in our lives. Interactions and activities that were once easy and natural can become more difficult. This beautifully illustrated book serves as a tool to facilitate dialogue with the very youngest in our families. It celebrates and honors the natural optimism of every child using the enduring, loving bond between grandfather and grandson as an example. It's about a boy who can only see the positive in what others perceive as his grandfather's disability and also portrays the optimistic and determined attitude of a grandfather as he continues to find joy in life despite the physical challenges that Parkinson's disease brings. (Best suited for preschoolers).

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Parkinson Society British Columbia
Société Parkinson Colombie-Britannique

CHAMPIONS FOR PARKINSON'S

RAFFLE

**PURCHASE TICKETS FOR YOUR CHANCE TO WIN
A ROUND TRIP FOR TWO TO ANY
WESTJET DESTINATION!**

**LAST CHANCE
TO BUY!**

Tickets:
1 for \$10

All proceeds benefit Parkinson Society British Columbia.
Help us make a difference.

Draw Date:

Tuesday, June 9, 2015 at 8:00pm

Me-N-Ed's 8th Annual Charity Golf Tournament

Riverway Golf Course, 9001 Bill Fox Way, Burnaby, BC



Parkinson Society British Columbia | 600 - 890 Pender Street, Vancouver, BC V6C 1J9
604 662 3240 | 1 800 668 3330.

For Rules of Play visit www.parkinson.bc.ca

Chances are 1 in 1,000 (total tickets for sale) to win. Actual odds depend on number of tickets sold.
BC Gaming Event Licence: # 74374

Problem Gambling Help Line 1 888 795 6111
www.bcresponsiblegambling.ca

Know your limit, play within it.

19+

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GROUPLINK
June 2015

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Parkinson Society British Columbia is committed to having the voices and concerns of the Parkinson's community heard. The key ingredient missing? **It's you!**

As a person living with Parkinson's or carepartner, you understand first-hand the impact that the disease can have on your life and the lives of your loved ones. Your stories are important tools in advocating for increased programming and supports.

Here are some tools to help prepare you to become an Advocacy Ambassador:

1. Background on the campaign for shorter waitlists [\[view\]](#)
2. Suggested agenda for meetings with MLAs [\[view\]](#)
3. Follow-up questions after a meeting with an MLA [\[view\]](#)

Interested in becoming an Advocacy Ambassador?

Contact Jean Blake at jblake@parkinson.bc.ca | 1 800 668 3330 | 604 662 3240

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MEET AN ADVOCACY AMBASSADOR: JEAN FRASER



Jean Fraser is a mother of two, and proud grandmother. Before retiring, her career included being a teacher, teacher-counsellor, vice principal and principal in K-12 public schools. She then took her experience and began supervising student teachers in their practicums, as well as teaching undergraduate and graduate classes at the University of British Columbia and University of Victoria.

As a runner, she participated in several 10km races and half-marathons, but began experiencing tightness and stiffness coupled with aches and pains in her knees and legs. At first, she considered these symptoms to be “normal” for an active, aging person, so she did not think much of it.

About three years ago, Jean began noticing a tremor in her right hand. A year later, she was able to see a neurologist who diagnosed her with PD. After receiving her diagnosis, she realized it was likely that she had been experiencing symptoms of PD for the last 10-15 years. All things considered, the progression of the disease for Jean has been quite slow, and for that she says she is quite thankful.

“I knew very little about PD prior to my diagnosis,” Jean says, “I’ve done a lot of reading and research since then, and as a result, I believe it’s important for people to talk more about the disease.” Jean now volunteers her time as an Advocacy Ambassador. “Parkinson’s is so much more common than I would have believed years ago, and I think there is still a lot of stigma surrounding some of the symptoms associated with it. This is a clear indication of the need for further education, and an organized effort to rally for the expansion of available supports and research.”

Jean’s first meeting took place with her MLA, Andrew Weaver. In listening to her story, Mr. Weaver revealed that he had a friend with PD, and was familiar with the disease. During the meeting, Jean says, “He was interested in my suggestions for ways to overcome the challenges we face with PD and wanted to know what further actions he could take.” When asked why she felt it was important for others to get involved with advocacy efforts, she replied, “Because PD is very individualistic, our stories are powerful tools in educating others and working towards common goals. Telling my story has also really helped me fight the loneliness and isolation that this disease can bring.”

**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!**

WWW.PARKINSON.BC.CA/SUPERWALK

DISCUSSION TOPIC: APATHY

Introduce the topic by asking these questions:

1. Have you experienced any symptoms of apathy?
2. How have symptoms of apathy and/or fatigue impacted your relationships?

.....

Introduction

Apathy occurs in as many as 50% of people with Parkinson's disease (PD) yet it remains one of the more misunderstood symptoms. Current research identifies apathy as a condition separate from depression and anxiety, two of the common mood-related symptoms of Parkinson's. While apathy is a separate condition, it is similar to depression and anxiety in that all three symptoms (apathy, depression and anxiety) are more likely caused by physiological changes in the brain than by psychological reactions to having Parkinson's. In short, apathy is often a biological disorder associated with PD.

People who experience apathy are generally less interested in taking part in activities that help maintain their level of functioning. This can be extremely frustrating for carepartners. Greater understanding of apathy and Parkinson's is very important for individuals with PD and their carepartners. The purpose of this Help Sheet is to give an overview of how apathy can differ from other Parkinson's related symptoms and to provide ideas for self-care and coping.

What are the symptoms of apathy?

Apathy relates to behavioural changes including but not limited to:

- reduced interest in people and activities
- reduced spontaneous interactions with others or with pets
- lack of motivation and decreased initiation of activities
- flat affect (an inability to express emotions)
- changes in mood and thinking
- little or no goal-directed behaviour

What causes apathy in PD?

Apathy in PD often results from physiological changes in the brain; specifically, disruption in brain pathways as well as decreased levels of dopamine. Some cognitive problems common to PD, such as short-term memory loss and difficulty initiating behaviours, are also associated with the development of apathy.

Apathy can also be caused by an individual's emotional reaction to living with a chronic condition. Apathy may be closely related to depression and anxiety, conditions which are treatable.

DISCUSSION TOPIC: APATHY (continued)

Apathy and depression

An individual who is experiencing apathy may have symptoms that are similar to those associated with depression, such as low energy and lack of interest. They may speak slowly or not at all for long periods of time. Apathy does not, however, share all cardinal symptoms of depression, for example:

- sadness
- hopelessness
- irritability
- thoughts of suicide
- anxiety

Apathy and fatigue

Fatigue is an extremely common symptom of Parkinson's. Fatigue has many similarities to apathy such as low energy, lack of interest in activities and low motivation. Fatigue, however, often relates to medication management. Bradykinesia (slowness of movement), dyskinesia and medication on/off periods can be unpredictable and exhausting. Improved medication management can provide some relief from these symptoms, and thereby reduce fatigue. If the symptoms of low energy, lack of interest in activities and low motivation are not resolved with improved medication management, they may be symptoms of apathy.

Apathy and motor symptoms of PD

It is common for people with PD to have decreased facial expression which can make a person appear sad or disinterested when, in fact, they are not. The "Parkinson's mask" is often misunderstood by carepartners and medical staff because the person appears apathetic.

Compounding this problem is the soft voice common to PD. Lack of facial expression and a soft voice can lead to erroneous assumptions on the part of others that the person with PD is apathetic and/or depressed. It is possible that the person with Parkinson's is not apathetic but, rather, is having difficulty expressing themselves.

The impact on carepartners

Apathy is a symptom that typically has a greater negative impact on carepartners than on a person with Parkinson's. Many carepartners report feeling frustrated with the person they care for and it is not uncommon for a carepartner to feel they are working harder than the person with Parkinson's.

Without an understanding of the nature of apathy in PD, a carepartner may start to see the person they care for as lazy, defiant, bored, difficult to motivate and generally unwilling to help themselves. This can become a highly stressful situation resulting in significant strain on the relationship.

Looking for more resources on mental health? Be sure to check out these:

- [Depression and Anxiety Helpsheet](#)
- [Cognitive Health Helpsheet](#)
- [Enhancing Communications](#)
- [The Other Face of Parkinson's: Mind, Mood and Memory](#)

RESEARCH

RESEARCH DISCLAIMER

Our monthly updates are a collection of recent articles that we have found on the Internet and in publications. They are offered solely on an informational basis. PSBC does not research or investigate the articles further and we do not provide additional follow up to verify that they are anything other than interesting. We urge you to do your own follow up on any of the information found in the articles presented. ***If you have any questions or concerns about the information contained in the articles ALWAYS check with your doctor.***

Research Profile: Professor Alex MacKay Measuring the Brain's White Matter and How it Affects Thinking in Parkinson's Disease

Research Project: Assessment of "normal appearing" white matter in Parkinson's disease and its association with cognitive dysfunction.

Pilot Project Grant: \$45,000

Project Description:

"Myelin (white matter) speeds things up by a factor of 100, but if you have a problem with myelin, this speeding-up doesn't happen. People don't think as well."

One of the substances in the central nervous system that appears critical for healthy thinking and reasoning is myelin – the fatty tissue known as white matter in neurons, which connects and conducts the signals cells send to one another. The more myelin, the faster those connections among cells.

At the University of British Columbia, physicist Alex MacKay and his colleagues have created a new technique using Magnetic Resonance Imaging (MRI) to measure the myelin in people's brains. Now, they're testing the theory that the breakdown or loss of myelin within the brain contributes to the problems in thinking and reasoning that many people with Parkinson's disease experience, sometimes before the stiffness, rigidity and tremors that more commonly flag their diagnosis.

MacKay and his team have demonstrated that people with multiple sclerosis have less myelin and also have cognitive problems, and drug companies are already testing medications that can either reduce or prevent the breakdown of myelin. If MacKay can demonstrate that the same process occurs in people with Parkinson's, the new drugs under development for MS and other diseases could ultimately help people with Parkinson's disease too. The companies will also have a way to tell if their drugs are repairing myelin or stopping its loss.

"It's a very exciting time," says MacKay. "Clinical trials are happening as we speak."

MacKay will use this non-invasive imaging technique to measure the myelin in the brains of people with Parkinson's disease, particularly in the frontal lobe, which controls judgment, reasoning and other forms of executive functioning. The people participating in the imaging study will also undergo cognitive testing, so the researchers can correlate their thinking and reasoning skills to their myelin measurements.

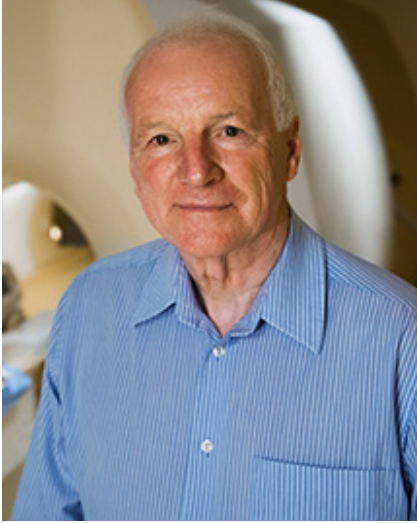
This is the first time researchers have used MRI scans to investigate a link between myelin and Parkinson's, and there is still a lot of work necessary to understand how myelin breakdown is related to the death of dopamine-producing cells, MacKay cautions. But he hopes this new line of enquiry will explain one portion of the Parkinson's puzzle – a puzzle in which he has a personal stake.

"I have two very good friends who have Parkinson's disease," says MacKay. "I relate very much to this disease and how rough it is on those who have it."

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RESEARCH

(continued)



Biography:

Dr. MacKay is a physicist who trained at Dalhousie, UBC and Oxford University. Dr. MacKay is a full professor at the University of British Columbia with a joint appointment in the Radiology and Physics & Astronomy departments. He directs the UBC MRI Research Centre and is co-Director of the Graduate Medical Physics Program at the University of British Columbia.

His entire research career has involved working with magnetic resonance techniques. Early on, he worked with the nuclear magnetic resonance in model membrane preparations and wood. Since 1988, he has been working on the development of advanced magnetic resonance imaging techniques for medical application.

Two decades ago, his research group pioneered a magnetic resonance technique which makes images of the myelin component of white matter. Myelin water imaging has by now been applied to a wide variety of neurodegenerative diseases, including multiple sclerosis, schizophrenia and phenylketonurea. This Parkinson Society grant will support the first application of myelin water imaging to Parkinson's disease.

CAREPARTNER'S CORNER

When Your “Get-up-and-go” Leaves You Behind: Apathy

One of the most common complaints from spouses of people living with Parkinson's sounds something like: “if he/she doesn't get up off the couch and do something instead of sitting all day watching TV, I'm going to scream”. Carepartners may start to see the person living with Parkinson's as lazy, disinterested, and unwilling to help themselves out, by doing their exercise and speech therapy, without being constantly reminded. This in turn is construed as nagging by the person living with Parkinson's. This type of stress often puts significant strain on a relationship. Sound familiar?

Well, in defense of individuals living with Parkinson's, they may be experiencing something called APATHY (or sometimes 'amotivational syndrome') that may occur at any time – even early in the disease process, before the motor symptoms show up. Apathy occurs in approximately 50% of people living with Parkinson's, and yet remains one of the most misunderstood symptoms.

The symptoms of apathy include:

- Reduced interest in people and activities
- Reduced spontaneous interactions with others
- Lack of motivation (not starting things on their own)
- Inability to express emotions
- Changes in mood and thinking
- Loss of motivation to pursue old activities they used to enjoy, such as hobbies
- Not speaking for long periods of time

People may mistake apathy for depression or anxiety. It is important to understand that apathy is seen as a separate symptom. These symptoms may happen separately or at the same time. While we do have effective treatment options for depression and anxiety now, research is still under way for apathy. This makes it important to have your doctor help sort out which symptom(s) you have, so that options can be tried.

Fatigue is another common symptom of PD. Like apathy, fatigue has such symptoms as low energy, low motivation and lack of interest in activities. Unlike apathy, fatigue often relates to medication management of the physical issues, whether symptoms like stiffness or dyskinesia, which can be exhausting. In other words, if the symptoms of low energy, lack of interest in activities, and low motivation are not resolved with improved medication management, they may be symptoms of apathy.

As if that is not enough, lack of facial expression and soft voice – two very common symptoms of PD – can lead to erroneous assumptions on the part of others that the person with PD is apathetic, depressed or even rude and disinterested: all of which can lead to the person living with Parkinson's being left out and isolated.

So what can you do? Start talking to your doctor as soon as symptoms of apathy appear, as it is important to discuss potential causes in order to assess what is going on. Things such as:

1. Screening for depression – investigate causes and treatment of depression
2. Investigate possible causes of fatigue and discuss treatment
3. Ensure your antiparkinson medication is providing the best possible physical symptom relief

Things that you can do for yourself would include:

1. Getting involved with an exercise group to enhance energy levels, as well as social interaction. You may not always feel like going, but it is important to push yourself, as the end result will be beneficial.
2. Participate in a support group. It is comforting to know that you aren't the only person dealing with apathy!

Carepartners, will hopefully now have a better understanding that their loved one's apathy results from physiological changes in the brain; specifically disruption in brain pathways as well as decreased levels of dopamine. It is not the case that your loved one is lazy and doesn't care about doing those speech and physical therapy exercises at home. Rather, he or she simply doesn't think to do them, even when a simple reminder brings the need to do something to mind. Demanding, arguing, begging, wheedling or haranguing is likely to produce a minimal effort at best.

The situation calls for flexibility, ingenuity and PATIENCE! When apathy is truly the reason your loved one struggles with meeting the demands of the day, it may become necessary to be gently directive, but not overly reactive. Don't let your frustration get the better of you, and start doing things for your loved one as things will only build up a sense of helplessness on their part.

Tips:

1. Negotiate a schedule for regular daily activities.
2. Mutually establish a list of household chores the PlwPD can reasonably manage.
3. Make it clear that diminished motivation is not the same as diminished responsibility.
4. Get timers, post reminders and cue with clear statements e.g. "the trash needs to go out".
5. If the negotiated activity is not done, it is reasonable to hold the person accountable and make it clear it is their own responsibility.

Apathy presents challenges to everyone in the family. While it can be a potential source of stress, it is also an opportunity to enrich relationships and build stronger bonds.

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www.parkinson.bc.ca

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