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JAN 2016

## UPCOMINGEVENTS

### SHAKE, SHAKE, SHAKE!

Join Emily Chambers, dynamic local vocalist, and other musical guests for Shake, Shake, Shake! Proceeds from this not-to-miss concert will benefit Parkinson Society British Columbia. This event is for ages 19+. Two valid pieces of ID will be required for entry.

Date: Friday, January 8, 2016  
 Location: The Imperial | 319 Main Street, Vancouver  
 VIP Reception: 6:30 pm - 8:00 pm  
 Concert: 8:00 pm (doors open at 7:00pm)  
 Tickets: VIP Reception \$125 | General Admission \$25  
 (VIP ticket purchases are eligible for a tax receipt in the amount of \$65)  
 Purchase tickets: <http://bit.ly/shakeconcertix>

### COMMUNICATION AND SWALLOW WORKSHOP

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 practise 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.

Date: Friday, January 29th, 2016  
 Location: Desert Gardens Senior Centre (540 Seymour St, Kamloops)  
 Time: 9:00 am – 4:00 pm  
 Facilitator: Sherri K. Zelazny, MA RSLP  
 Registration: <http://www.parkinson.bc.ca/kamloops-workshop>

### YOUNG ONSET PARKINSON'S DISEASE, 4 WEEK SERIES

This series will provide emotional and educational support to people who have been diagnosed with Parkinson's under 50 years of age. It will explore topics on: YOPD diagnosis and symptoms, coping and adapting, disease progression and health concerns, living well with YOPD and importance of exercise.

Date: Every Tuesday in February beginning February 2, 2016  
 Time: 7:00 pm - 8:30 pm  
 Location: Delivered via webinar. An internet connection is required.  
 Registration: <http://www.parkinson.bc.ca/yopd-webinar>

## REGIONAL CONFERENCE NANAIMO

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.

Presentations and speakers at this conference will include:

- Parkinson's Overview | Dr. Martin McKeown
- The Neurological Effects of Exercise in Parkinson's Disease | Matthew Sacheli
- Nutrition and You | Elietha Bocskei, MSc, RD
- The Benefits of Mindful Living | Cindy Fisher, RCC
- Get Moving | Doug Pickard

Date: Saturday, February 20, 2016

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

Location: Vancouver Island Conference Centre, Mt. Benson Ballroom D | 101 Gordon St, Nanaimo ([map](#))

Cost: Member \$30.00 | Member (Couple) \$50.00  
Non-Member \$40.00 | Non-Member (Couple) \$70.00

Registration: <http://www.parkinson.bc.ca/nanaimo-conference-2016>

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## BRAIN HEALTH FAIR

**SAVE THE DATE!** Friday, April 15, 2016 at the Vancouver Convention Centre, Vancouver, BC, Canada

The Brain Health Fair is a free, daylong event connecting hundreds of neurology patients, families, and caregivers affected by a brain disease, as well as students interested in brain science and the general public interested in brain health. The program is designed and executed by neurologists, with local and national experts, who are on hand to answer questions about the wonders of the brain and the latest research advances.

For more information, please visit: <http://patients.aan.com/go/activities/brainhealthfair>

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## WORLD PARKINSON CONGRESS

Date: September 20 – September 23, 2016

Location: Oregon Convention Center  
(777 NE Martin Luther King Jr Blvd, Portland, OR)

Registration and block hotel bookings open January 11, 2016.

Will you be joining us in Portland for the WPC 2016 and have an interest in music, voice and Parkinson's disease? [Learn more](#) about the secret project with Marimba Artist and Choir Director Judi Spencer!

Parkinson Society British Columbia will be offering travel grants to the World Parkinson Congress in 2016. Stay tuned for further information in the new year.

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

## NEW DIAGNOSIS DAY VIDEO RESOURCES

Missed New Diagnosis Day? No problem. To make our educational events more accessible, we are piloting recording some of our key sessions. On Saturday, November 14, 2015 we held our New Diagnosis Day in Langley, BC. Recordings from these sessions are available for public viewing, free of charge, at: <https://vimeo.com/album/3671975>

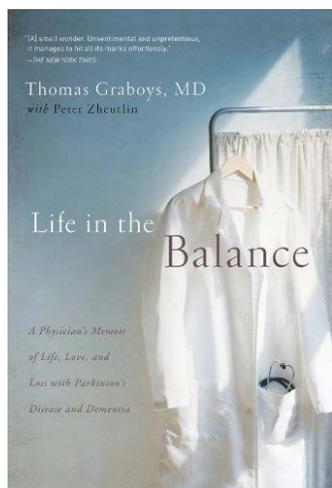
### *What is New Diagnosis Day?*

Experts lend their knowledge to present on topics that provide an overview of the disease, treatment options and tips on staying active to help slow the progression of symptoms. There is also the opportunity to hear from a panel of people with Parkinson's and carepartners to learn from those who have experienced adjusting to a diagnosis first-hand.

Presentations/discussions include the following:

<i>What is Parkinson's Disease?</i>	Dr. Daryl Wile, MD, MSc, FRCPC
<i>Adjusting to a New Diagnosis</i>	Courtney Hanna, RCC
<i>Panel Discussion</i>	Stephen Gardner, Pat Mauch, John Hougan & Margaret Mutch
<i>Stay Active and Exercise</i>	Naomi Casiro

## FEATURED BOOK



*Life in the Balance: a physician's memoir of life, love and loss with Parkinson's disease and dementia by Thomas Graboys, MD with Peter Zheutlin*

At the age of 49, Dr. Thomas Graboys had reached the pinnacle of his career and was leading a charmed life. A nationally renowned Boston cardiologist popular for his attention to the hearts and souls of his patients. Today, Graboys is battling a particularly aggressive form of Parkinson's disease and progressive dementia, and can no longer see patients or give rounds. Despite the physical, mental, and emotional toll he battles daily, Graboys continues his life-long mission of caring for the world one human being at a time by telling his story so that others may find comfort, inspiration, or validation in their own struggles.

Four copies available in our [lending library](#).

## RESEARCH STUDIES

Vancouver Coastal Health (VCH) Professional Practice and the Neurological Rehabilitation Outpatient Program (NROP) team at Lions Gate Hospital (LGH) are investigating *the effects of exercise on walking, balance and Quality of Life (QoL) in people living with Parkinson Disease (PD)*. For more information, please visit: <http://bit.ly/ExerciseQoLStudy>

Researchers at the University of British Columbia are interested in talking to patients with a diagnosis of Parkinson's disease, their caregivers, and healthcare providers, about their views on advance care planning (ACP) for end of life health care decisions. This might include importance future decisions related to: medications, treatment, artificial nutrition and hydration, mobility, and/or cognition at end of life. For more information, please visit: <http://bit.ly/ACPStudy>

## PHYSICIAN SPEARHEADS NEW CLINIC

Dr. Daryl Wile, who recently relocated to the Okanagan, began exploring the possibility of opening a specialized Parkinson's disease program/clinic in Kelowna while working as a Clinical Movement Disorders Fellow at the Pacific Parkinson's Research Centre in Vancouver. That possibility is now a reality as the Okanagan Movement Disorder Clinic officially opened to patients in September 2015.



### **The Okanagan Movement Disorder Clinic**

The Okanagan Movement Disorder Clinic is housed in Kelowna General Hospital and is the result of a partnership between Dr. Wile, Interior Health, the University of British Columbia Faculty of Medicine, the Parkinson Society British Columbia and Parkinson's disease support groups.

Its goal is to provide clinical care and improve services for people with Parkinson's and other movement disorders throughout the Okanagan. "We are developing a program of specialized care for Parkinson sufferers right here in the Interior," says Dr. Wile. "Our goal is not only to provide great medical care, but also to advance research in Parkinson's and to help train new doctors."

The clinic currently operates one day a week with the support of a nurse and a medical office assistant providing services such as counseling and education for patients with Parkinson's disease and other movement disorders including ataxia, chorea, tics and dystonia.

### **UBC Involvement and Opportunities**

The UBC Faculty of Medicine has also helped develop the clinic into a teaching site for UBC medical students and residents as well as creating opportunities for research collaborations. One area of emphasis is in lifestyle changes that benefit the disease, such as exercise.

### **Referrals**

For more information regarding referrals and any other movement disorder questions, please contact Dr. Wile's community practice by phone 250-862-4070 or by fax 778-478-2186.

## Sleep Disturbances: How to get a good night's rest



If you have Parkinson's disease (PD) you need enough sleep to ensure that you are rested and have the energy needed to effectively manage your symptoms, and to obtain the maximum benefit from your medications. A refreshing sleep may even offer you "sleep benefit", a period when you remain symptom free after waking.

Despite this need, you may find your sleep disturbed by a number of factors. Sleep disturbances are commonly experienced among people with PD which can significantly reduce their ability to function. According to research the primary sleep-wake cycle can be deregulated among those

with PD causing them to have fragmented sleep patterns. Up to 50% of people with PD will have REM Sleep Behaviour Disorder (RBD). This may cause excessive daytime sleepiness and fatigue.

Here are a few suggestions to help you get a good night's rest:

- Switching to a longer lasting or extended release form of medication, only with the direction of your neurologist or doctor, might help control your symptoms throughout the night.
- A regular afternoon nap of at least an hour, on the bed, will refresh you for the evening. A nap allows you to rest your muscles, relieving tension and aches.
- Sleep on your side. If your back or hips are sore, put a small soft pillow between your knees.
- If you can roll over without difficulty, spend at least 20 minutes a day on your stomach with your chin resting on your folded arms. This gives the spine an excellent stretch and relieves tension.
- Avoid strenuous exercise, hot baths or showers for two hours before bedtime.
- Don't go to bed hungry.
- Use the bed for sleeping rather than watching late night television or balancing bank statements.
- Ask your doctor about taking melatonin before bed. Melatonin is a natural hormone made by your body's pineal (pih-knee-uhl) gland. Or, you can ask about taking a low dose of a muscle relaxant, such as clonazepam. It is extremely important that you do not treat yourself for these disorders and that you discuss them with your doctor or neurologist in order to determine the best form of treatment for you.
- If you are disturbing your bed partner's sleep or vice versa, consider the occasional night in separate rooms. Alternatively, you may consider replacing one large bed with two three quarter or twin size beds with separate mattresses and covers.
- You may find it easier to be independent in bed if one side is up against a wall for you to push against.

Sleep Disorders such as RBD are common among people with PD. People with RBD do not have the normal muscle relaxation during sleep that others do. This causes them to act out their dreams during the REM stage of sleep. They may kick, shout or punch because their body is responding to their dreams

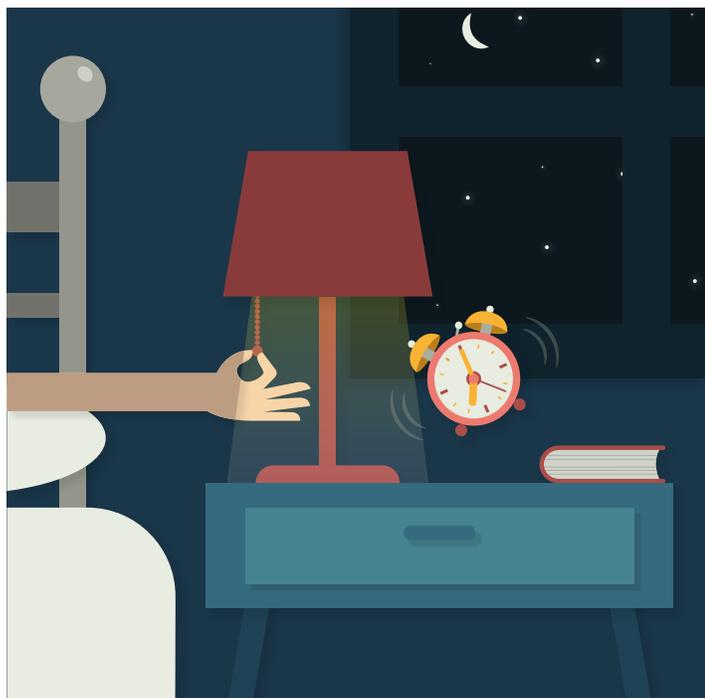
Other sleep disorders may affect someone with PD's sleep such as sleep apnea and Restless Leg Syndrome (also called Willis-Ekbom Disease). Sleep Apnea involves irregular breathing patterns during sleep, for instance pauses in breath or shallow breathing throughout the night.

Restless Leg Syndrome typically occurs during the evening and characterized by an intense urge to move the legs or other limbs and is accompanied by uncomfortable symptoms of tingling or pulling sensations. These disorders are commonly found in those with PD and can be treated with the appropriate attention from your doctor or neurologist.

Talk to your movement disorder specialist or neurologist if you are experiencing sleep disturbances.

Sources: Pacific Parkinson's Research Centre, University of British Columbia, Vancouver, BC; Parkinson Society British Columbia, Doctor's Alert!: Sleep Disturbance in Parkinson's help sheet; National Parkinson Foundation, [www.parkinson.org](http://www.parkinson.org), USA

## Getting Adequate Sleep as a Carepartner/Caregiver



Adequate sleep is essential to staying healthy and functioning well whether or not you have PD. As a carepartner, you need sleep to do your daily work safely, to cope with emotional stress, and to carry on giving care. Yet if you are caring for someone with PD, you may not be getting enough sleep.

Researchers have found that 95% of family members who provide palliative care have serious sleep problems. These problems are becoming better understood, and increased attention is being given to caregivers' sleep problems, especially in those caring for people with cancer, dementia, Parkinson's disease, or children with illnesses or disabilities.

Family caregivers often minimize their sleep problems and hesitate to talk about them with the health care team. You may feel your sleep is less important than what is happening with the person in your care. You may think you can get by with limited sleep and catch

up in the future. Unfortunately, this lack of sleep is more likely to catch up with you.

Many factors contribute to poor sleep for caregivers. It may be one or a combination of the following factors:

- **Changes in routine.** When you care for someone, you have less time for fresh air, exercise or relaxation, which promote sleep, and you may consume more caffeine (e.g. coffee, tea, coca cola, chocolate), which inhibits sleep.
- **Change in sleeping environment.** You may sleep on a couch or temporary bed to be near the person you are looking after. You may be disturbed by the nighttime noise made by special equipment, such as an oxygen concentrator, alternating pressure mattress, or even a baby monitor you may use to listen for calls for help.
- **Worry.** You may have trouble falling asleep or may wake up in the night because your mind is busy thinking about your concerns. Some caregivers talk about wanting a remote control to 'shut it off' or 'change the channel'.
- **Lack of help with over-night care.** The programs and services in your area may be limited, which makes it difficult to find respite care at night. You may find it hard to hand over responsibility or trust the care provided by others. The person who is ill may not be willing to accept outside help.
- **Needs of the person who is ill.** As the person in your care becomes weaker, he or she will need help during the night as well as during the day. Your sleep may be interrupted because you need to help with toileting, repositioning or medications. The person may have trouble sleeping if symptoms such as pain, shortness of breath or restlessness are not well controlled. If the person in your care is unable to sleep, chances are you will be unable to sleep as well.

- **Grief.** You may have trouble sleeping after the death of a loved one. This may be due to poor sleeping habits developed while caregiving, or it may be part of the mental and emotional sifting that happens during the grieving process.

Regardless of the cause, your lack of sleep has consequences for you and for the person in your care. Your overall physical and mental health may change. Your body may not be able to fight off a cold or flu as usual, or you may experience flare-ups of an existing health problem, such as high blood pressure. You may feel less able to cope with the emotional ups and downs and stresses of providing care. You may have memory problems, or trouble thinking clearly. Also, sleep disturbance has been linked with depression.

## Managing your sleep

It is important to talk to the health care team about any sleep difficulties, either yours or those of the person you are caring for. In each case, it is important to ask the health care team for help for both your sakes. Together, you and the team can explore ways to promote sleep and rest. It may help to talk to someone; a hospice volunteer, social worker, spiritual care provider or counsellor may help you find ways to reduce your worries and link you to services and supports. Call PSBC counsellors 1.800.668.3330 if you are feeling overwhelmed at home.

Many caregivers do not like to take sleep medication, because they worry about not hearing the person they are caring for, or being too sleepy to provide care in the night. Talk to a doctor about the possibility of taking a sleep medication, like melatonin, if other attempts to promote sleep have failed.

Don't be afraid to ask for help with caregiving. Asking for help is not a sign of failure. You do not have to do everything on your own. Sometimes it makes a big difference to ask for even a small bit of help. For example, you can ask someone to cover for you while you take a nap or sleep overnight two or three times a week. Contact your local home health office to set up in-home support. Click on the health authority below to access home and community care information.

- [Fraser Health](#)
- [Interior Health](#)
- [Northern Health](#)
- [Vancouver Coastal Health](#)
- [Vancouver Island Health](#)

These are some things that may help you improve your sleep:

- Try to maintain a regular sleep-wake schedule as much as possible.
- Set up a bedtime routine that lets you unwind a bit before you turn out your light. It may help to have a bath, wash your face and hands, change into pajamas, brush your hair and apply lotion to your face and hands.
- Notice what helps you relax, and make that part of your routine. You might listen to soft music, read a bit, watch a funny TV show, or pray.
- Try to grab even a few minutes every day for exercise and fresh air if at all possible.
- Nap when you can, but try to avoid the late afternoon and evening, unless you know you will be awake during the night to provide care.

- It may help to do some relaxation or visualization exercise. Ask your health care team to help you learn how to do this.
- Go to bed when you feel drowsy in the evening, rather than making yourself stay up until a set time. This helps you avoid lying awake in bed.

Sources:

[http://www.virtualhospice.ca/en\\_US/Main+Site+Navigation/Home/Topics/Topics/Providing+Care/Sleep+and+Caregivers.aspx](http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Providing+Care/Sleep+and+Caregivers.aspx)

<https://www.agingcare.com/Articles/reasons-caregivers-need-sleep-151983.htm>

## EXECUTIVE COMMITTEE

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