

Vol. 35, December 2014

Wearable Sensors for Parkinson's

Inside...

Message from the Coordinator	2
Upcoming Programs	3-5
Light Therapy	6
Placebo Effect of Fake PD Treatment	7
Understanding Pharmacare	8-9
Building a Resilient Life after Diagnosis of Parkinson's	10
Speak Up for Parkinson's App	11
Care Partner's Corner	12
Resources	13
From Headway	14



The Michael J. Fox Foundation and Intel Corporation are partnering to gather and analyse Canadian data from Wrist-worn devices worn by people with Parkinson's that track users' movement. The results could help individuals and their doctors better manage their Parkinson's.

A study was launched earlier this year to evaluate three wearable devices for tracking measurable features of Parkinson's such as slowness and frequency of movement.

People with Parkinson's wore the devices during two clinic visits and at home over a few days. Intel engineers are comparing the data obtained from the devices to clinical observations and patient diaries in order to test the devices' accuracy. They are developing mathematical formulas to measure the symptoms and the progression of Parkinson's. These devices can capture up to 300 observations per second. So formulas to interpret all that data and report what it means related to someone's Parkinson's can help individuals and their physicians monitor disease.

The next phase of the MJFF-Intel study will capture data to measure medication response such as on/off episodes. Recruitment is expected to begin soon in locations including New York City, Boston and Tel Aviv, Israel. The Michael J.Fox Foundation plans to expand their use to other clinical studies.

Contact

202-1640 Oak Bay Avenue
 Victoria, BC V8R 1B2
 Phone: 250-475-6677
 Fax: 250-475-6619
 Email: help@vepc.bc.ca
 Web:
 www.headwayvictoria.com

For more information go to :
<https://www.michaeljfox.org/foundation/news-detail.php?watch>



A Tribute to Robin Williams

By Maureen Matthew, BSW

I remember him in the movie Patch Adams. Robin brought alive the powerful impact of using humor to enrich the quality of life of children with cancer. And, in countless other movies, we laughed and cried as he showed us his ability to see the comedy of life, to touch our souls and to act with remarkable spontaneous intellect. Thank you Robin for lightening our lives and reminding us of the power of positivity and humor to shift our perspective.

“No matter what people tell you, words and ideas can change the world.”

- Robin Williams

The shock of learning of his early stage Parkinson’s diagnoses has touched a nerve for many. Yes, Robin struggled with depression and addictive coping strategies for a long time. But, how do we make sense of his decision to end his life and what role did his Parkinson’s play in his choice? We’ll never know the answer. Instead, let’s reflect on the strong association between the onset of Parkinson’s and the correlation with a clinical depression or an anxiety form of depression. Symptoms can be subtle and most of the people I meet with Parkinson’s would not describe themselves as depressed. However, those with tremor often tell me that they find their tremor worse with stress and seeing the tremor escalate increases their anxiety. Others report that they have a stronger response to life’s stressors and a tendency to ruminate on repetitive thought patterns of negativity or worry. Some on medication describe panic attacks, particularly at times when their dopamine levels drop before their next dose is due. Dopamine is known to be a “feel-good neurotransmitter”, so it’s understandable that a drop in dopamine would affect emotional wellbeing. Chronic stress is tiring and we cannot expect ourselves to function well when we have cumulative stress and fatigue. So, bottom line message is to please address any mood changes with loved ones, with physicians and with your circle of support. There are many treatment options including self care, integrative strategies and medical management. A few options are described in this newsletter. The article on melatonin and light therapy are examples from the pool of options one can explore. The power of a common bond of experience is well recognized, so coming together with others with Parkinson’s can be deeply therapeutic. We’re here to light your path when you forget...Lindsay and I are here to support you and we both feel honored to do so.

Hugs,

Maureen Matthew



Robin Williams
1951 – 2014

We are deeply saddened by the passing of Robin Williams. He inspired us through his passion, his generosity, and the gift of laughter. He will be greatly missed.

Upcoming Programs

Victoria Parkinson's Wellness Workshops

Group sessions are facilitated by Maureen Matthew, Parkinson's Program Coordinator. Meetings are on a drop in basis at The Salvation Army Citadel 4030 Douglas St (North of McKenzie). Suggested donation is \$10 each to cover expenses or at your discretion.



Session: Parkinson's Self Management – Exploring Fatigue & Insomnia

Date: Tuesday, January 27, 2015 **Time:** 1:30pm-3:30pm

Description: Maureen will facilitate discussion of the factors that lead to fatigue & insomnia and strategies to address them. We welcome your challenges, your successes and your desire to enhance your energy.

Session: Communicating Effectively with Physicians in BC's Healthcare System

Date: Tuesday, March 31, 2015 **Time:** 1:30pm-3:30pm (date to be confirmed in next NL)

Description: You may have experienced the time constraints of physicians and waiting lists for access. Care of people with Parkinson's is complex, especially if combined with other health conditions you may be living with. Dr Ben How, a local primary care physician, will talk about his years of experience in patient care and some key strategies to help you partner with physicians for win/win outcomes.

Session: Keys to Successful Management of Parkinson's

Date: Wednesday, April 29, 2015 **Time:** 1:30pm-3:30pm **Location:** To be held at the Salvation Army Citadel 4030 Douglas St, North of McKenzie.

Description: Dr Parbeen Pathak, local neurologist, will discuss the elements of managing Parkinson's that can enhance your function and quality of life. Half of his session will be a Q & A period.

Special Teleconference Events (Pre-Registration required)

Session: Vision Changes & Parkinson's



Date: January 20, 2015 **Time:** 7:30pm for 30minutes by phone. **Location:** This is a phone meeting so questions must be submitted to Maureen one week prior to January 20.

Description: Dr. Ted Atkins, neuro-ophthamologist, will be on the phone with moderator Maureen Matthew to review some specifics of sight that may impact people with Parkinson's. This can be difficult to tease out given age-related visual changes. In either case, visual problems contribute to falls, so hope you can join us. Registrants will receive a set of simple steps to participate in this practical phone approach to hearing an expert's opinion.

Upcoming Programs

Parkinson's Support Groups

Session: Chronic Disease Self-Management Program

Date: January 23 - February 27, 2015 **Time:** 1:30-3:30pm **Location:** Headway

Please register in advance with Lindsay Beal at 250-475-6677 or via email at lbeal@vepc.bc.ca

Description: Coordinated by UVic, this course offers a fabulous approach to problem-solving and goal-setting. Step 1 is to decide if you are ready and motivated to explore your part in making your life better in spite of PD or whatever health concern you wish to focus on. Gratefully, no matter what your chronic health condition, this 6 week program has something to offer. Topics include: coping with stress, exercise and exploring if you've got all the bases covered, nutrition, handling fatigue, and communicating with your health care team.

Session: Sidney & Westshore Parkinson's Support Groups

Group sessions are facilitated by Lindsay Beal, Parkinson's Outreach Coordinator. Drop-in basis.

Sidney Group - Meets 1st Tuesday of every month (Sept-June)
Time: 1:30-3:30pm **Location:** Saanich Peninsula Presbyterian Church, 9296 East Saanich Rd. Suggested donation of \$4.

Westshore Group - Meets 3rd Tuesday of every month (Sept-June)
Time: 1:30-3:30pm **Location:** Alexander Mackie, 753 Station Ave.

Description: Group discussions are introduced through topics of interest and relevance to living well with Parkinson's. Sessions are rich with personal life experience, caring respect for one another and a wealth of practical information and wisdom. Special guests include Sue Decker, Speech Pathologist attending in January and Dr. Marsh presenting in March, on treatments, current research, the placebo effect and symptoms.



Motionways

For more information or to register, contact Lindsay Beal, Parkinson's Outreach Coordinator at 250-475-6677 or lbeal@vepc.bc.ca



Description: Motion Ways is a movement meditation class. Using music and various attentiveness exercises, Lindsay Beal facilitates a process of exploration, creativity and mindfulness. This is an opportunity to dance without steps, to go at your own pace, and to follow your physical needs. It runs one hour each week.

Upcoming Programs

Special Workshop for Care Partners (Pre-Registration Required)

Please register for these sessions by calling Maureen at 250-475-6677 or via email at mmatthew@vepc.bc.ca

Session: Exploring How to Get Help When You Need It



Date: Wednesday, January 14, 2015 **Time:** 10am-2:30pm **Location:** The Salvation Army Citadel Suggested donation of \$10.

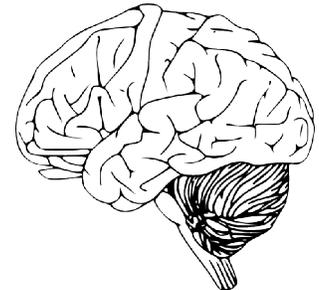
Description: Planning ahead can be a wonderful way to manage stress. This brown bag workshop will include: types of PD challenges that may benefit from outside help now or later, the role of our agency to assist you in managing PD and care challenges, knowing who to call for services and what to ask for, private sources of help in the community, and an opportunity to hear from others' experience in using services. Maureen Grant is a social worker with Island Health (formerly VIHA). She has 30 years experience working in Home & Community

Care and she is a gift to those she serves. We are grateful that she will be present to describe current service options and how to maximize benefits available.

Session: Understanding Cognitive Changes in Parkinson's

Date: Wednesday, April 1 & 15, 2015 **Time:** 1:30pm-3:30pm **Location:** The Salvation Army Citadel Suggested donation of \$10.

Description: This is a 2 part workshop specially designed for family members on their own. Kaitlyn Roland, PhD has been studying Parkinson's brain function for years. In the first session, we will learn about changes that occur in the Parkinson's brain and how those brain changes can contribute to the presentation of cognitive symptoms. Kaitlyn will review the different elements including memory, thinking, task-sequencing, visuospatial, language, and reasoning. In the second session we will discuss how these cognitive symptoms challenge daily living and effective strategies to support a loved one. This will be an interactive series rich with your own experience and practical ideas.



Congrats Lindsay!

Before we forget, the 35th annual GoodLife Fitness Victoria Charity Marathon took place on early Sunday morning, Thanksgiving Day long weekend. A whopping \$141,024 was raised through the entire charity program (approximately \$3000 raised by Headway alone). A big congratulations to Lindsay Beal (Parkinson's Outreach Coordinator) and Sonya Dhudwal (Epilepsy Program Coordinator) for completing the 8K race and raising money for the agency.

Calendar of VEPC Programs Events

January to March 2015

Date	Time	Topic	Venue	Register (R) Drop-In (DI)	Cost
Tuesday Jan 6	1:30 - 3:30	Speech and Swallowing	Sidney	DI	Don.
Wednesday Jan. 14	10:00 - 2:30	How to Get Help When You Need It (Care Partner Workshop)	S.A. Citadel	R	Don.
Tuesday Jan 20	1:30 - 3:30	Speech and Swallowing	West Shore	DI	Don.
Tuesday Jan 20	7:30 p.m.	Vision Changes and Parkinson's	Phone	R	Free
Fridays Jan. 23 - Feb 27	1:00 - 3:30	Chronic Disease Self Management	HeadWay	R	Free
Tuesday Jan. 27	1:30 - 3:30	Managing Fatigue and Insomnia	S.A. Citadel	DI	Don.
Tuesday Feb. 3	1:30 - 3:30	Discussion: Games and Health	Sidney	DI	Don.
Tuesday Feb. 17	1:30 - 3:30	Discussion: Games and Health	West Shore	DI	Don.
Tuesday Mar. 3	1:30 - 3:30	Research and Issues of Parkinson's	Sidney	DI	Don.
Tuesday Mar. 17	1:30 - 3:30	Research and Issues of Parkinson's	West Shore	DI	Don.
Tuesday Mar. 31	1:30 - 3:30	Communicating with your Health Team	S.A. Citadel	DI	Don.
Wednesday Apr. 1	1:30 - 3:30	Understanding Cognitive Changes in PD (Care Partner Workshop Part 1)	S.A. Citadel	R	Don.
Tuesday Apr. 7	1:30 - 3:30	Discussion: Efficiency at the Dr. Office	Sidney	DI	Don.
Wednesday Apr. 15	1:30 - 3:30	Understanding Cognitive Changes in PD (Care Partner Workshop Part 2)	S.A. Citadel	R	Don.
Tuesday Apr. 21	1:30 - 3:30	Discussion: Efficiency at the Dr. Office	West Shore	DI	Don.
Wednesday Apr. 29	1:30 - 3:30	Keys to Success with PD	S.A. Citadel	DI	Don.

For registration:
Call 250-475-6677

Or e-mail mmatthew@vepc.bc.ca or
lbeal@vepc.bc.ca

HeadWay
202-1640 Oak Bay Avenue

Sidney
Saan. Pen. Presbyterian Church
9296 East Saanich Rd.

Sally Ann Citadel
4030 Douglas St.
(Turn North off McKenzie)

West Shore
Alexander Mackie
753 Station Avenue

Light Therapy Shows Promise in Parkinson's

Excessive daytime sleepiness (EDS), fatigue, sleep disorders and depression—all common challenges for people with Parkinson's (PD)—reportedly improve with exposure to light. Now new research indicates that light therapy may be beneficial for people with PD. Melatonin, a hormone produced in the pineal gland located near the center of the brain, follows a daily biorhythm in which levels rise at nighttime and drop in response to morning light. The body's natural sleep-wake cycle is referred to as a circadian rhythm. Because the production of melatonin, which triggers sleepiness, is disrupted by exposure to light, researchers have postulated that exposing people to bright light could have a therapeutic benefit.



Aleksandar Videnovic, MD, and his colleagues at Northwestern University, an NPF Center of Excellence, published a small study that uncovers some of the mysteries of sleep-wake disturbances in PD. Dr. Videnovic is now at Massachusetts General Hospital, Harvard Medical School, an NPF Center of Excellence, and is continuing his research there. The study involved 35 people, 20 with PD and 15 without PD, whose blood melatonin levels were checked every 30 minutes for 24 hours.

They discovered that people with PD didn't secrete melatonin in a normal pattern. And those with PD who suffered from EDS had more dysfunction in the patterns of melatonin secretion than those without EDS. How long they had PD, how severe their motor symptoms were, and what medications they were taking were not related to the circadian rhythm function. The researchers suggest that the circadian system could be strengthened by timed exposure to bright light and exercise.

Several other small studies have shown that both motor and non-motor symptoms may be improved with light therapy. In May, Dr. Videnovic and his colleagues presented the preliminary results of a second study on bright-light therapy for EDS. This study involved 30 Parkinson's experiencing EDS. Participants were randomized to receive either bright light therapy or dim red-light therapy for two hours a day for 14 days. The results showed that EDS, as measured on the Epworth Sleepiness Scale, improved by 2.2 points in the dim red-light group and by 4.2 points in the bright-light group. This research suggests that light therapy could be optimized to improve EDS in people with PD.

If exposure to light suppresses melatonin production but improves PD symptoms, why would anyone take melatonin? Melatonin is also an antioxidant, and neurodegenerative disorders such as PD have been linked to oxidative damage and free radical generation. Some people believe that melatonin may slow or block neurodegeneration. However, no human studies support this theory. Others use melatonin for its effects on sleep disturbances, but no large, well-controlled studies support this notion either. In fact, reports have surfaced indicating that melatonin replacement may actually worsen sleep in PD.

Editor's Note: As with many supplements and non-traditional therapies, the science is not clear yet, but worthy of personal exploration and discussion with one's physician.

Source: National Parkinson Foundation. (2014). *What's hot in parkinson's disease? Light therapy shows promise in Parkinson's*. Miami, FL: Okun, M.S.

Doctors Unravel the Placebo Effect of Fake Parkinson's Disease Treatment



In a new study examining patients with advanced Parkinson's disease, neurologists say they've identified parts of the brain that control placebo effect, raising hopes of singling out people most susceptible.

But they're still very much in the dark about underlying causes of one of medicine's great mysteries. Some people, when given fake treatment, actually get better, but others, for whatever reason, do not. Stranger still, some people improve at the mere suggestion of future treatment.

The placebo effect is a problem for clinical researchers because they need to know which treatments work and which don't. When people respond well to treatments they aren't actually given or that don't actually work, it skews the results. That's why, for years, doctors have been trying to figure out how placebo works and why.

"While they may appear to be mysterious, placebo responses have discernible neurophysiological mechanisms," wrote the authors of a companion commentary in *The Journal of Clinical Investigation*. To learn more about those mechanisms, neuroscientists at the Feinstein Institute for Medical Research in New York chose 45 patients with Parkinson's disease for a double-blind study. All of them would receive brain surgery, but only 22 would receive actual treatment. The other 23 were given fairly routine operations designed to do nothing.

The doctors weren't looking for signs of placebo effect — they already knew it would happen. Patients with Parkinson's disease, the second most common neurological illness behind Alzheimer's, have previously shown an incredible sensitivity to the idea of treatment. A 2001 study illustrated that dopamine released at the expectation of possible healing had healing benefits by itself. "Expectations," doctors wrote in another study, "have a strong influence on the subsequent emotional experience of both" pain relief and reward processing.

Instead, what David Eidelberg and colleagues at the Feinstein Institute were looking for was what happened inside their brains before and after the brain surgery. Using PET scans, they measured activity in parts of the brain associated with negative emotions, expectancy and placebo-induced anti-depressive effects. After the placebo surgery, 16 of the 23 patients performed better on tests of their motor functioning. Seven saw no improvement.

Here's the interesting thing: Those 16 patients had very little activity before surgery in the parts of the brain that are activated by placebo. The other seven had more activity in the region all along. So that's the good thing — research doctors may now have something to look for when they want to weed out placebo-receptive test patients.

Researchers still have no clue how a little dopamine and anti-depressant brain activity relates to improved motor function. "The final effector pathway remains obscure," wrote Mariya V. Cherkasova and A. Jon Stoessl in their commentary. But they say one thing is more clear from the study — expectation didn't have anything to do with it. The knowledge of participation in clinical trials did not induce placebo effect.

In a sad coda to the study, one year after their placebo brain surgeries, the Parkinson's patients were unblinded. That is, their doctors revealed that they had been in the sham surgery group and not the treatment group. Immediately, the parts of their brains that are activated by placebo reverted to their normal state. With that, their small gains in motor functioning disappeared, too.

Source: Wolford, Ben. (2014). Doctors unravel the placebo effect of fake Parkinson's disease treatment. Retrieved on October 27, 2014 from <http://www.medicaldaily.com/doctors-unravel-placebo-effect-fake-parkinsons-disease-treatment-293760>

Understanding Pharmacare Special Authority for Parkinson's Medications

Living with any complex condition is challenging physically, mentally and financially. Navigating our Provincial Ministry of Health and healthcare system can be a maze. This overview provides some insights into the resources available to anyone in BC to get the best medication therapy and maximize financial support from Pharmacare.

What is Pharmacare?

Pharmacare is the provincial body that funds prescription medications in BC. As a BC resident you are entitled to, but must apply for, Fair Pharmacare coverage. You can visit the Fair Pharmacare website at <http://www.health.gov.bc.ca/pharmacare/fpcreg.html> or call 1-800-663-7100 for more information .

Once registered, you are assigned a yearly deductible based on your family's income that must be paid for out-of-pocket before Pharmacare coverage will kick in. This deductible has two tiers. When you hit the first tier, Pharmacare will begin paying for 70% of your medication. Once you hit the second tier, or your full deductible, Pharmacare will begin to pay for the full cost of your medications. Pharmacare coverage is based on the provincial formulary, a list of covered medications .

Pharmacare offers increased assistance to families experiencing financial hardship. For example if your family net income has decreased by more than 10% since last year, or if your spouse is now a resident in long term care you can apply to Pharmacare to have your deductible reassessed. Another option to pay your deductible is to contact Pharmacare and set up a monthly payment plan to spread medication costs evenly throughout the calendar year as opposed to incurring high costs early in the year.

Parkinson's Medications and Pharmacare Special Authority

Unfortunately, not all Parkinson's medications are currently covered on the provincial formulary. Those medications that are not covered are an out of pocket expense. In addition these expenses do not apply to the individual's Pharmacare deductible.

However, Pharmacare does cover some Parkinson's medications via the Special Authority process. The list of medications covered by Special Authority includes drugs that are not usually the first choice of treatment, or for which there may be less expensive alternatives. In order to qualify for Special Authority, your doctor must write or call Pharmacare to register you for a Special Authority medication and you must meet the eligibility criteria determined by Pharmacare, which are outlined in the table below.

It is important to note, if you apply for Special Authority and you are approved, you are still subject to your remaining Pharmacare deductible, so medications may not immediately get less expensive. However, once you are approved for Special Authority, your Parkinson's medication cost will apply toward your deductible. Please note that this will not work retroactively, so if you purchase Pramipexole in January and then qualify for it to be covered via Special Authority in February, the money you spent in January will not apply to your annual deductible, but your next purchase would apply toward the deductible.



Understanding Pharmacare Special Authority for Parkinson's Medications (Cont'd)

The following Parkinson's medications are eligible for Pharmacare Special Authority:

Generic Name	Criteria	Approval Period
Entacapone AND entacapone. levodopa/carbidopa combination tablet (Brand name: Comtan and Stalevo)	As adjunct therapy for patients with an inadequate response (defined as significant "wearing off" and/or severe motor complications i.e. Fluctuations) after alterations of levodopa/carbidopa doses	Indefinite
Pramipexole (Brand name Mirapex)	For the treatment of idiopathic Parkinson's disease PLUS 1. Patient cannot tolerate or has contraindications to levodopa or bromocriptine OR 2. Patient is receiving adjunctive treatment with levodopa and cannot tolerate or has contraindications to bromocriptine	Indefinite
Ropinirole (Brand name: Requip)	For the treatment of idiopathic Parkinson's disease PLUS 1. Patient cannot tolerate or has contraindications to levodopa and bromocriptine OR 2. Patient is receiving adjunctive treatment with levodopa and cannot tolerate or has contraindications to bromocriptine	Indefinite

If you feel that you meet the circumstances outlined above please contact your physician or specialist immediately and ask her to apply on your behalf. For the drugs listed in the table, the coverage provided with Special Authority will not expire.

You can see the complete list of medications that require Special Authority, and their eligibility criteria, under Pharmacare Limited Coverage Criteria at www.health.gov.bc.ca/pharmacare/sa/saindex.html or talk to your doctor or pharmacist.

At Heart Pharmacy IDA, we believe that the patient care is of utmost importance. Interacting with patients, via medication reviews, which we affectionately call Heart to Hearts, allow us to understand all your health care needs and work with you to ensure you have the best medications and the best coverage possible. If you have any questions about this article or if you would like to schedule your Heart to Heart, please feel free to stop in at any of our locations or call me directly at 250-477-2131.

Jennifer Carefoot, Pharmacist

Building a Resilient Life after a Diagnosis of Parkinson's



Author: Dr. Maria Sirois is a clinical psychologist, an inspirational speaker and a featured presenter at the Kripalu Center for Yoga & Health in Stockbridge, Massachusetts. She is the author of *Every Day Counts: Lessons in Love, Faith and Resilience* (2006).

“That commitment to stay positive and help others through humor and support demonstrates what we call the power of AND—Yes, I have a Parkinson’s diagnosis AND my life is bigger than this diagnosis. For people with Parkinson’s disease, this simple shift in outlook can help them build resilience.”

A few years ago, a man attended one of my presentations at the Kripalu Center for Yoga & Health. He had a natural sense of humor. Soon after, he decided to establish a Parkinson’s support group in his area. He made one request of himself: bring a joke to each meeting and therefore begin with positivity. Resilience isn’t about going it alone, and pulling yourself up by your boot straps. Instead, resilience is about facing reality exactly as it is, and using tools and strategies that help you live a meaningful and purposeful life. Fortunately, we now know that resilience can be increased at any age in any situation.

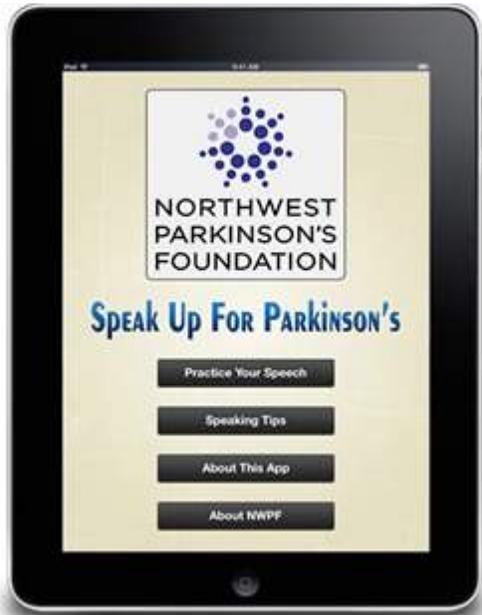
Here’s how:

- **Identify your strengths.** In a time of stress we want to lead with our strengths. People who do this have more control over situations than they realize. Our top strengths or signature strengths help us feel more confident and efficacious because they’re who we already are at our vital core. Make a list of your top talents and gifts. Or, visit www.viacharacter.org and take the VIA Survey, a scientifically validated character strength quiz. Then, look for ways to align your day with those strengths.
- **Be present.** For people with PD, finding ways to feel less anxious and more in control is critical. One way to stop those high tension thoughts is through a daily meditation practice such as mindfulness or deep breathing. This will help you develop the habit of becoming calm when facing stressors, and once you are calm you can think more creatively and make healthier choices.
- **Know who’s on your team.** There are three types of connections you need in order to build resilience. Your team should include credentialed experts such as doctors and therapists; others with Parkinson’s for mutual support; and, your choir—those individuals you bond with on a very deep level and can lean on in the hardest of times.

So the next time you’re having a bad morning, take a moment to ask yourself three questions: What strengths are going to help me feel confident today? How can I remain calm? Who can I lean on? These are the practices that strengthen us and increase our overall well-being. You want to treat yourself as your own best friend. Resilience is a choice and choosing practices that nourish you will change your experience of your diagnosis and will uplift your life.

Source: National Parkinson Foundation, Inc. (Summer 2014). *Parkinson Report*. Retrieved from <http://www.parkinson.org/Parkinson-s-Disease/PD-Library/NPF-Publications/Parkinson-s-Report>

Speak Up for Parkinson's App



This app was developed by a group of elderly people whose objective was to develop a product, idea or process that would improve the aging population's quality of life. They called themselves The DaVinci Group.

One of the members, Hal Newsom (who is a longtime supporter of the Northwest Parkinson's Foundation) has Parkinson's. He has had a difficult time speaking so that people can understand him. He found a "Talking Dog" app for his iPad that he could talk to and his words would be repeated, although in a cartoonish voice by an animated dog. He discovered that this feedback was helpful in assisting him to learn to enunciate better. He figured that if there were an app that would realistically record his voice and actually show a video of his face and lips moving it would help a great deal.

The DaVinci Group took on the challenge and soon partnered with Sandcastle Web Design & Development (a web and mobile application developer) and the Northwest Parkinson's Foundation (for funding, marketing & distribution). Through several months of design, development and testing – which included speech therapist Roberta Kelly of the Virginia Mason Medical Center who has extensive experience in working with Parkinson's patients – the Speak Up for Parkinson's app became a reality.

The Speak Up for Parkinson's app is a tool for people with Parkinson's to practice their speech. The approach pays special attention to the volume of the person's voice, which is a key factor in addressing speech impairment. Two practice tools are included:

Words and Phrases: A series of random statements are presented for the user to speak;

Reading and Conversation: A free-form area allowing longer practice sessions.

With both tools a volume meter is provided, which is paired with audio-video feedback. The app also provides helpful speaking tips and additional information. iPads and iPad minis with iOS 7 are compatible to download this application.

Source: Sandcastle Web Design & Development. (2014). Speak up for Parkinson's app. <http://www.sandcastle-web.com/nwpf/support/>.

Care Partner's Corner

Can taking care of someone make you happier?

Yes! There are certainly challenges and tough days, but there are also many times of expressing love in ways big and small, learning to be truly present, and even laughter.



Fulfillment.

Being able to provide physical, emotional, or spiritual support to someone, or all of the above, is not a one-way street - caring and helping others is deeply gratifying, rewarding and uplifting.

Happiness.

Many caregivers express the wonderful things they cherish about their role as a care partner - renewed sense of purpose and belonging, great pride in being a caregiver and moments of incredible laughter and happiness.

The little things.

A short chat with a friend, a regular early morning run, 20 minutes to draw or paint, or even caring for something else like a garden or your dog, can help you refuel for challenging times ahead.

Stronger Relationships.

You might get to know the person better, or in new ways, during the experience of providing care. A 2012 Stats Canada study, Caregivers in Canada, found that about 9 in 10 caregivers felt the experience was rewarding. Moreover, 7 in 10 also expressed that their relationship with their care receiver had strengthened over the course of the previous 12 months.

Smart Spoon May Simplify Meal Time

Some people might be interested in a new high tech spoon that may counteract tremor by introducing counter movements. It's not cheap...\$295.



“Being able to see somebody eat on their own for the first time, or even just eat better, has been a hugely impactful thing,” said Pathak.

The device costs \$295, though LiftLabs also accepts donations to help those who cannot afford to buy one.

Excerpted from:

<http://www.voanews.com/content/smart-spoon-allows-parkinsons-sufferers-to-feed-themselves/1830217.html>

For more information, visit

<http://www.theguardian.com/technology/2014/nov/25/google-launches-smart-spoon-shaking-hands-liftware>

Resources

Parkinson's Inreach at the West Coast College of Massage Therapy (WCCMT)

The Massage therapy students at West Coast College of Massage Therapy (WCCMT) need experience with care of those with neurological conditions like Parkinson's. They therefore offer access to their student services at the rate of \$12/hr for those with PD. A care partner may also be able to receive the rate of \$20/hr. This inreach program is available on a first come first served basis. To access, please contact Maureen Matthew at 250-475-6677 to confirm your eligibility. She will send you the required documentation. If the Inreach service is full, you can also use student clinic service at a more affordable rate than professionals charge. If you have extended health insurance, you may wish to check out your massage coverage.

Free and Online "Ask the Expert" Forums

Ask the Doctor: A team of Parkinson's specialists answer medical questions about Parkinson's disease.

Ask the Speech Clinician: A team of experts answers questions regarding speech and swallowing.

Ask the Pharmacist: Mark Comes, RPh, fields questions about medication management.

Visit parkinson.org/forums for detailed, step-by-by instructions for registering and logging into the forums.

Volunteers!



WE NEED YOU!

We are looking for **Silent Auction volunteers** to solicit and collect auction items for the upcoming Charity Golf Tournament in June 2015. If this is of interest to you, contact Monica at monicapowell@shaw.ca



We offer our compassion to the families who have lost the following loved ones and extend our sincerest thanks to those who sent donations in their memory:
Nancy Cole, James Earl, Joy Te Kampe, Fred Little, Brian McKenzie, Joan Waller, Patricia Walton, Barry Watson, and Louise Williamson.



From the Executive Director

It is the time of year to appreciate members, volunteers and clients that have included HeadWay, Victoria Epilepsy & Parkinson's Centre in their busy lives. Whether it has been through financial donations, volunteer time spent with our programs and activities, or support and advice that you have shared with us; it is very much noticed and appreciated. It is the membership voice that drives the Society's programs, so please communicate with us when you have something to say.

Your Annual Membership

This is the time of year to renew your membership with HeadWay, Victoria Epilepsy and Parkinson's Centre. Early in 2013, the Victoria Epilepsy & Parkinson's Society changed the membership fee structure to reflect full donation tax receipts. Although changing the structure of our membership nearly two years ago has caused some confusion, the silver lining has been that communication with us has really increased and we learned more about the role we play in our members' lives.

Memberships are free and run January 1st – December 31st. We do rely upon personal donations and planned giving to continue the programs and services.

What are the benefits of being a Member?

- A vote at our Annual General Meeting
- Reduced fee for outreach programs, educational services, conferences
- Receive our newsletters (electronic or hardcopy - upon your request)
- Involvement in our ongoing campaign to support Parkinson's and Epilepsy through the services the Centre provides

How do we benefit from your membership?

- Allows us to conduct business as a charitable organization
- You offer us advice about our services
- You offer us a volunteer base to assist and support us with our campaigns and fundraising events
- Allows us to apply for and receive grants and funding to support our services:
 - Professional consultation services with information and knowledge about diagnosis, management and understanding epilepsy or Parkinson's
 - Support and advocacy with community, school and work situations
 - Professional referral base
 - Parkinson's and epilepsy lending library
 - Newsletters BrainWave and Transmitter
 - Online information (ex. website, newsletters, e-blasts)

If you are renewing your membership or if there are any changes to your contact information, please send us a quick email or phone call at 250-475-6677. Email addresses offer the most efficient way to send you our newsletter and event information. New membership forms are available at our office, can be downloaded from our website, and will be included in our winter campaign letter. For an electronic copy, follow this link: http://www.vepc.bc.ca/about_us/membership.html.

From the Community Awareness & Education



“The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart.”

- Helen Keller

Oh Helen, what a wise woman. I remember coming across this Helen Keller quote decades ago and really loving the meaning behind it. Yet, it took a number of years for the significance of the quote to truly become apparent to me. Being Headway’s new Community Awareness and Education Coordinator, I feel fortunate to have the opportunity to try and transpose that quote from words to reality. Health education and community awareness are not concrete objects that can be seen or touched, but what they can do is empower individuals to gain the tools they need to support themselves; and this sense of taking control, is what is felt by the heart. Coming from a Public Health background, I truly believe that health education and promotion is crucial to ensure the best health of our society. Unfortunately, the importance of health promotion and education has been heavily underrated. This position allows me to educate and raise awareness for those with Parkinson’s through in-service presentations for healthcare professionals, students, caregivers, among many others. The in-service presentations we offer provide a wide range of information spanning from an overview of seizure first aid, coping strategies, medication information, support tips for caregiver’s - and that is only to name a few. Every presentation is designed to cater to the specific audience in mind. I am also the social media coordinator for Headway so if you haven’t already, please “like” our Headway Facebook page. It provides regular updates on Headway events, articles that we think may be of interest to you, and photos of Headway in the community.

Lastly, being the editor of the newsletter that you currently have in your hands, if there is anything that you would like to see in the next issue - please let me know! If you have an article that you would like to submit for the next issue, send me an email (contact info listed below) and we would love to share your work.

I look forward to my work with the Headway community and am eager to see what the new year has to bring!

Amanda Ng, MPH
250-475-6677
ang@vepc.bc.ca



From all of us at Headway,
Happy Holidays!

Advertising Guidelines

Acceptance of advertising does not constitute an endorsement by the Victoria Epilepsy & Parkinson's Centre of the products or services listed.

Distribution: 800 Victoria & Vancouver Island

Seasonal Issues: Fall, Winter, Spring/Summer

For ad rates, format, deadlines and payment options please contact Della Truitt, VEPC Office Manager, at (250) 475-6677 or email: help@vepc.bc.ca

Confidentiality Guidelines

We respect your right to privacy, so please be assured that our agency does not share our membership list with outside individuals or organizations. Occasionally we may ask you to volunteer some information so that we can better understand our clients' needs and improve our services.

Newsletter Support
provided by:



Please Note:

Our website is now www.headwayvictoria.com but is being quickly redirected to www.vepc.bc.ca while we change over. We remain the **Victoria Epilepsy and Parkinson's Centre** (not VEPC and not Headway) for any cheque payments.

"The Transmitter"
Published seasonally
Editor: Amanda Ng
Canadian Mail Publications
Agreement #40050532

DIRECTORS:

President - Ross Young
Vice-President - Andrew Trinder
Treasurer - Fiona Bayliss
Secretary - Sheri D. Welsford
Alanna Holroyd
Nathan Lampard
Dr. Alex Henri-Bhargava
Matt Peulen
Charles Meadow
John Pereira

STAFF:

Executive Director -
Barbara Gilmore MPubRel
Parkinson Program Coordinator -
Maureen Matthew, B.S.W.
Epilepsy Program Coordinator
Sonya Dhudwal, MSW, RSW
Parkinson's Outreach Coordinator -
Lindsay Beal, M.Ed
Community Awareness Coordinator -
Amanda Ng, BSc, MPH
Accounts- Della Cronkrite

EDITOR'S NOTE: Our newsletter and education meetings provide a range of information which does not necessarily reflect the views of our agency. Please use your discretion and consult your physician.

Publications Mail Agreement No. 40050532
Return Undeliverable Canadian Addresses to:

Victoria Epilepsy & Parkinson's Centre Society
202-1640 Oak Bay Avenue
VICTORIA BC V8R 1B2

IMPORTANT CHANGE OF ADDRESS NOTICE - To reduce agency costs for newsletters returned with incorrect addresses, please keep us informed of any change in your address so that we can ensure you receive the newsletter