



A Life Restricted by Nothing

Deirdre Syms, HeadWay Epilepsy Services Manager

Like many others, I have a tradition of looking at my life and setting goals during certain times of the year – my birthday and New Years, for example. This year will be particularly exciting because I have been completely seizure-free for a while now and that always changes how I view my life options. Does 2019 see me riding horse-back on a beach, swimming in the ocean, or driving to all my appointments rather than hopping on a bus? Do I finally take up scuba diving or try my hand at a theatrical production now that I will worry less about messing up and embarrassing myself?

Likely, I will not try many of the things above, but there is true beauty in the dream that I could now do everything – a life restricted by nothing! More likely, I will live with the thought (in the very back of my head) that my seizures could return. It has happened to me before after long stretches of being seizure-free, so it is best for me to be cautious. How comforting it would be to not worry about it so much though! I could walk up stairs without fear of falling, walk across the street without fear of getting hit by a car, go swimming or take a bath without fear of drowning! Forever the optimist, I live in hope that the last seizure I had will be the last of my life while preparing for the worst. If I do have seizures again, I will always try to find a way to bring joy and happiness into my life the best way I can. It can be a struggle, but I believe that struggle is worth it!

To help with some of our epilepsy struggles, we are offering some great programs and events for 2019. Please take a look at our programs and events on the following pages and sign up for anything that interests you.

I hope you and your family had a wonderful holiday season and a fabulous New Year. May all the blessings of the season be with you now and throughout the year.

Vol.47, Winter 2019

Special points of interest:

- New services for people up-island
- Purple Month is fast approaching!!!
- New 4 part Nutrition and Slow-Cooking series.
- Article: New Epilepsy Warning Device could Save Thousands of Lives

Inside this issue:

New Programs & Workshops
p. 2-4

Dr. Sealey Cannabis
Information
p. 5

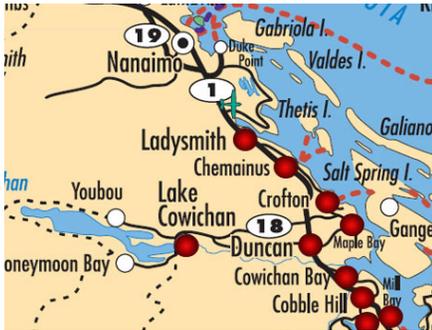
Groups
p. 6-7

Volunteer Opportunities
p. 8

Community Partners
p. 9

Article: New Epilepsy Warning Devices could Save thousands of Lives
p. 10-11

Services across the Island starting in January with Deirdre Syms



January 31, 2019 HeadWay will be in Duncan for one-on-one consultations. Book your spot today!

We are now offering a number of services, such as peer groups, up island for any individuals who live with any form of epilepsy. If you are interested in meeting others in your area, please let me know at epilepsy@vepc.bc.ca or call 250-475-6677 to get connected.

Personal one-on-one consultations and community education programs will now be offered once a month in a variety of communities up-island.

If you are interested in meeting with me personally, or if you have an organization at which you would like me to speak, please send me a message at epilepsy@vepc.bc.ca, or call 250-475-6677 to get on the list.

Our first visit will be to the Duncan area on Thursday, January 31, 2019.

Medical Qi Gong comes in January



“Qi Gong is an ancient form of exercise and healing that focuses on breathing concentration and energy flow.”

Dr. Steven Aung

We have a Qi Gong instructor coming to offer classes with our partner Absolute Therapy (just across the hall from our office). Classes start Thursday January 3 from 10:00-11:00 am.

You will be guided through the fundamentals of Medical Qi Gong. We will focus on breathing patterns to help us become aware of the circulation of Qi (vital energy) throughout your whole being - body, mind and spirit.

If you are interested in joining our Medical Qi Gong class, please email epilepsy@vepc.bc.ca or call 250-475-6677 to get on the list.

For more information about Qi Gong please visit victoriaqigong.wordpress.com

Dr. Sare Akdag returns in February, 2019

February 2019

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
27	28	29	30	31	1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	1	2

*Mark your calendars!
Last session sold out in
record time, so please email
epilepsy@vepc.bc.ca or call
250-475-6677 to get on the list
if you are interested in this
seminar.*



*This program will likely
be scheduled for Thursday
afternoons once we have
15-18 participants who
have completed their
referrals.*

Neuropsychologist, Dr. Sare Akdag, joins us again to continue the conversation about Cognition and Learning in Children with Epilepsy.

Dr. Akdag will present at HeadWay on February 21, 2019 6:30 p.m. to 8:30 p.m.

For those who attended Dr. Sare's first workshop in May on Cognition and Learning in Children with Epilepsy, you already know what an incredible evening it was! The cost for this workshop will be \$25.

BCALM's Art of Living Mindfully Program

BCALM's Art of Living Mindfully Program is now accepting referrals for the HeadWay group. If you are interested in attending but do not yet have a doctor's referral, please get it in straight-a-way! And please make sure it is the referral form marked "HeadWay". This allows our clients to attend a great program without having to sit on BCALM's regular wait list.

"This 8 week course provides participants with a firm grounding in mindfulness based strategies useful in navigating stress and in recognizing patterns of thought, speech and behavior that may be contributing to stress and suffering.

Home meditation practice is a major component of this course in order to embody concepts learned in class and to then apply them into life. Exercises focusing upon mindfulness and cognitive behavioral therapy complement the meditation practice and allow participants to further explore key concepts of inquiry, acceptance, non-attachment, compassion, loving kindness and non judgement" (BCALM website).

Please email epilepsy@vepc.bc.ca or call 250-475-6677 if you are interested in attending this program.



Start the new year safe, healthy and on budget!

Deirdre Syms

Have you read the latest version of Country Grocer's Friends and Family magazine? Check it out, our nutrition and food series is featured!

To help our community keep on track with any health and wellness resolutions, we partnered with some brilliant minds to create a four-part Nutrition and Slow Cooking series, starting this coming February. For me, and some of you, the kitchen is a place that poses potential safety risks, which is why I'm excited to take part in this series.

Slow cookers help me maintain my independence but I tend to repeat the same meals. I am looking forward to learning new recipes and picking up some tricks and tips from Chef Michael. Plus, when we finish we all go home with an individual or family slow-cooker!

Feb. 4, 2019 from 6:30 – 8:30 p.m., join naturopaths Dr. Pam Hutchison and Dr. Stephanie Bayliss as they discuss nutrition. Suggested cost for this session is \$25.

Feb. 11, 2019 from 6:30 – 8:30 p.m., we welcome local celebrity Chef Michael Williams who will lead us in making a delicious slow cooker recipe. We will enjoy a finished version of the meal at the end of the session. Each participant or family will receive a slow cooker for this session. Suggested cost for this session is \$25.

Feb. 18, 2019 from 6:30 – 8:30 p.m., help us celebrate Family Day with a potluck supper at HeadWay. Bring your family and favourite food to celebrate with our community! There is no additional cost for this evening.

Feb. 25, 2019 from 6:30 – 8:30 p.m., join us for a food budgeting workshop to learn a variety of tricks and tips to make sure your hard-earned money goes the farthest it can! There is no additional cost for this evening.

If you are interested in attending any or all of these sessions, please email epilepsy@vepc.bc.ca or call Deirdre at 250-475-6677.

Note: No one will be denied access to any of our offerings based on inability to pay. HeadWay is an inclusive organization and we encourage everyone to participate.



The Cannabis Conversation

Dr. Rob Sealey kicks off Purple Month with The Cannabis Conversation on March 4, 2019 from 6:00 - 8:00 p.m.

Many of our clients have tried cannabis or hemp products such as CBD oil in an effort to decrease seizures, but they do so with very little objective information. We are thrilled that Dr. Sealey is coming to help us sort it all out.

“A typical presentation includes a description of the endocannabinoid system, history and evidence behind medical cannabis, potential therapeutic indications, dosages, administration, side effects, and contradictions”
drrobsealey.com

Please email epilepsy@vepc.bc.ca or call 250-475-6677 to get on the list if you are interested in attending this presentation and let us know if you have specific questions you would like to ask Dr. Sealey.

Chronic Condition Self-Management Facilitator Training is now full.

Thank you to everyone who signed up for the Chronic Condition Self-Management Facilitator Training in January. This training program is now full. Once our volunteers are trained, we will be able to offer this 6-week program to our clients. It's an interesting and informative program that comes with a free and amazing textbook. The program itself is offered through UVIC and Self-Management BC at no charge to its participants.

The first session is tentatively booked for Fridays from 2:00 – 4:00p.m., February 7 – March 14, 2019.

HeadWay's Chronic Condition Self-Management Program

If you are interested in enrolling in this program, please email epilepsy@vepc.bc.ca or call 250-475-6677 to get on the list.

There is no cost to enrol in this program.



Join a group! Connect with others with seizures and participate in interesting and fun things to do with each other.

Adults Group at HeadWay

Runs monthly on the second Wednesday, 12:30 – 2:00 p.m.

This group welcomes adults living with epilepsy. Participants share personal empowering stories to help each other live with hope and optimism. Participants also often use this group to collect ideas to solve a particular issue they are experiencing.

Youth and Young Adults Group at various locations

Runs monthly on the fourth Wednesday, 6:30 – 8:00 p.m.

This group welcomes participants under 30, or young at heart, who are interested in creativity and fun. Participants may meet out in the community, play pool, go to a movie or simply chat.

Parents/Children/Family Group at Pearkes Recreation Centre

Runs monthly on second Wednesday, 6:30 – 8:00 p.m.

This group welcomes families affected by epilepsy. This group focuses on sharing stories, acknowledging issues, making suggestions, and building a community of support. The children have a great place to play. If you are considering having a child, this is also the group for you!

First Nations Group

The third Monday of each month from 12:00 – 1:00 p.m.

This group welcomes those First Nations participants who are interested in a group with a First Nations perspective. We are pleased to welcome Shane Baker as the facilitator for this group. Shane is Métis and Wilp Gwininitxw of the Lax Gibuu – the Wolf clan of the Gitxksan. He's a proud Indigenous man living in Victoria who serves his community in many ways, including by working with youth and addictions.

Please note that First Nations participants may join any and all groups that interest them. This group is for those who want First Nations connection and perspective as part of their journey.



Purple Day Crafts Program

Every second Tuesday from 6:30 – 8:30p.m.

Purple Day is quickly approaching and we want to make a big purple splash! We are currently making friendship and rainbow loom bracelets for children to wear at purple day events at their schools. Come and be crafty!

If you see a fit call us and we will help create a connection. If you have an idea for a different group let us know!

Neighbours – Friends – Family Group

This new group welcomes neighbours, friends, and family to meet, share stories, learn more about seizures, and connect with and support each other.

Caregiver Group

This new group welcomes those who are caregivers for people with epilepsy. Share ideas, go out together in the community, and connect with and support each other.

Online Group

This new group welcomes those who live too far away to attend our groups in person, or those who simply prefer an online format. Choose a peer group and join us through Zoom!

Facebook Group

This group welcomes those who prefer to communicate through social media. Join a chat, post interesting research or share advice in this online format.

Walking Group

Please call if you are interested in creating a new walking group in the Greater Victoria area or would like to join a group.

Social Group

The new group welcomes those who want to get out into the community and do something fun. Possible outings include movie nights, dinners, going for coffee, going to a park, or anything else the group decides to do!

Register in advance with Deirdre 250-475-6677 or email epilepsy@vepc.bc.ca for any groups or clubs.

If you want to join through Face Time, Skype, or Zoom, just let us know!



Do you want to help individuals in your community? Then we want you!

We are starting several volunteer-based programs for which we need more volunteers. If any of the following programs interests you, please contact Deirdre at epilepsy@vepc.bc.ca.

All volunteer positions at Headway Victoria Epilepsy and Parkinson's Centre require an application process including a current vulnerable sector criminal record check prior to starting the position.

Purple Day Committee

Join us to help plan event around town to bring awareness to epilepsy.

Family Support Program

This program aims to support parents with seizures who may be required by the Ministry of Children and Families to have supervision while playing with his or her children. The cost of supervision falls to the parent with seizures, which can be a heavy burden. This program can also be accessed by parents who need connection and support. A volunteer orientation is required for this program.

Community Support Program

This program aims to support those who are isolated in our community. Volunteers may meet clients for coffee, go for a walk together, go grocery shopping together, or simply have a good chat. Preference will be given to those living successfully with epilepsy.

Note: If you would like to access the services of our Family and Community Support Programs, please let us know and we will match you with a volunteer.

We couldn't do it without a little help from our friends in the community...



Disability Resource Centre

Are you interested in applying for Person with Disability (PWD) status? The Disability Resource Centre has a weekly drop-in information session Thursday's at 1:30 p.m.

Tools for Success

Does your child with epilepsy need extra support in school? The Centre for Outreach Education (CORE) program, through the University of Victoria, offers specialized tutoring for children with a variety of challenges. Please contact Karen Efford at core@uvic.ca if you are interested in this program.

FND Hope Canada



Dr. Gheis recently started a non-profit organization that offers support and treatment for patients with functional neurological disorders in a group setting. Functional neurological disorders include psychogenic non-epileptic seizures (or pseudo-seizures). This program requires a referral from a physician. Please speak to your physician if you are interested in participating in this program.

Hope Air



Sometimes your health care needs cannot be met in Victoria and you will have to travel off the island. If you need to travel for medical care, Hope Air makes flights available Canada wide. Once you have your medical appointment booked you can contact this non-profit organization and book a trip for yourself and one travel companion. Only round trip flights can be scheduled. Call toll-free 1-877-346-4673.

New Epilepsy Warning Device could Save Thousands of Lives

Research

07 November 2018

Thank you to ehealthnews.com for sharing this article.

“Consortium researchers have therefore developed a bracelet that recognizes two essential characteristics of severe attacks: an abnormally fast heartbeat, and rhythmic jolting movements.”

A new high-tech bracelet, developed by scientists from the Netherlands detects 85 percent of all severe night-time epilepsy seizures. That is a much better score than any other technology currently available. The researchers involved think that this bracelet, called Nightwatch, can reduce the worldwide number of unexpected night-time fatalities in epilepsy patients. They published the results of a prospective trial in the scientific journal *Neurology*.

SUDEP, sudden unexpected death in epilepsy, is a major cause of mortality in epilepsy patients. People with an intellectual disability and severe therapy resistant epilepsy, may even have a 20% lifetime risk of dying from epilepsy. Although there are several techniques for monitoring patients at night, many attacks are still being missed.

Consortium researchers have therefore developed a bracelet that recognizes two essential characteristics of severe attacks: an abnormally fast heartbeat, and rhythmic jolting movements. In such cases, the bracelet will send a wireless alert to carers or nurses.

The research team prospectively tested the bracelet, known as Nightwatch, in 28 intellectually handicapped epilepsy patients over an average of 65 nights per patient. The bracelet was restricted to sounding an alarm in the event of a severe seizure.



The patients were also filmed to check if there were any false alarms or attacks that the Nightwatch might have missed. This comparison shows that the bracelet detected 85 percent of all serious attacks and 96% of the most severe ones (tonic-clonic seizures), which is a particularly high score.

For the sake of comparison, the current detection standard, a bed sensor that reacts to vibrations due to rhythmic jerks, was tested at the same time. This signalled only 21% of serious attacks. On average, the bed sensor therefore remained unduly silent once every 4 nights per patient. The Nightwatch, on the other hand, only missed a serious attack per patient once every 25 nights on average. Furthermore, the patients did not experience much discomfort from the bracelet and the care staff were also positive about the use of the bracelet.

“If applied globally, it can save thousands of lives.”

These results show that the bracelet works well, says neurologist and research leader Prof. Dr. Johan Arends. The Nightwatch can now be widely used among adults, both in institutions and at home. Arends expects that this may reduce the number of cases of SUDEP by two-thirds, although this also depends on how quickly and adequately care providers or informal carers respond to the alerts. If applied globally, it can save thousands of lives.

Johan Arends, Roland D. Thijs, Thea Gutter, Constantin Ungureanu, Pierre Cluitmans, Johannes Van Dijk, Judith van Andel, Francis Tan, Al de Weerd, Ben Vledder, Wytse Hofstra, Richard Lazeron, Ghislaine van Thiel, Kit C.B. Roes, Frans Leijten, and the Dutch Tele-Epilepsy Consortium. Multimodal nocturnal seizure detection in a residential care setting.

Neurology Oct 2018. doi: 10.1212/WNL.0000000000006545.

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.

Canadian Mail Publications Agreement #40050532
Return Undeliverable Canadian Addresses to:
Victoria Epilepsy and Parkinson's Centre Society
202-1640 Oak Bay Avenue, Victoria BC, V8R 1B2



HeadWay - Victoria Epilepsy and Parkinson's Centre is your local HUB for our epilepsy community. We were established in 1982 and feel privileged to be part of this community, providing support, care, knowledge to over 1000 people.

For more information about HeadWay, the services we provide, or epilepsy please contact:
Deirdre Syms at epilepsy@vepc.bc.ca

For more information on how to make a donation please contact:
Tania Fritz at tfritz@vepc.bc.ca