

Headlines



a newsletter for brain tumour patients and their families

fall 2018



By Daniel Ouellette

NOTHER DAY, ANOTHER TRIP to my "spa." I arrive at the end of the purple line to the Unit 4 radiotherapy suite, my 2nd home for another 4.5 weeks. I usually have a one liner ready for my radiation therapy wizards: "Yes, I would love a warm blanket and geez, if only the treatments were longer, I would bring cucumber slices and treat those bags under my eyes while I'm under the mask. And a mimosa afterwards will do nicely, thank you!" My humour is a big part of me; it is part of my armour.

Tim is my partner of 20 years and husband of 5 years. We live in the diverse and

colourful west end of Vancouver with our little long-haired dachshund, George. We love our hood, and are surrounded by family and close friends. We love to travel, have seen so much of this planet and still have many places we plan to see.

I've worked in Adult Education my entire career, and my most recent role entailed lots of travel and motivational speaking for groups as large as 100. My sense of humour and sunny disposition helped me connect in an authentic way with participants and allowed us to share feelings and experiences honestly. I believe that sometimes "you have to fake it until you make it," and have done this throughout my life.

Come February 2017, I had to put my money where my mouth was. It was then that I learned of the presence of a mass in the left side of my brain, resting near the area that controlled movement of my right side. Finally there was an explanation for the seizures that began in March, 2016. Initially the plan was to simply control the seizures with medication and monitor the growth of the mass. Why risk surgery until it was clear that we had to move forward with it?

Unfortunately, my seizures worsened and required three medications to reduce them from 30 to 3 a day. I had to leave work and couldn't be left alone. This led me to seek a surgical solution to my problems in the spring

of 2018. Tim had taken a leave of absence from work in order to care for me and I was no longer willing to sacrifice my quality of life or his. My diagnosis was made after surgery in May, 2018: a grade 3 oligodendroglioma.

You can see from this story that my journey began well before my cancer diagnosis. Two years of uncertainty, waiting and processing. This was especially excruciating with the onset of the daily seizures which had such an impact on our lives. But I was blessed with much support and love from family and friends and know that not everyone is so fortunate.

I strive every day to persist and stay positive. I get a lump in my throat when I see the colourful children's play area at the radiotherapy unit and recall my grandmother's words: "Dan, there are always others with heavier crosses to bear." On tough days, my armour helps me feel in control. We all can grow our own personal armour – it could be humour, meditation, prayer or whatever you use to find strength and control.

I write a Facebook blog/post every morning. I attempt to keep it funny, but I suspect many friends think it's a bit crazy and sometimes dark too. But this life has many shades to it and one has to ride them all. I try to be creative and active in all aspects of my life, so that I don't feel isolated and in an effort to keep things "normal." Not easy with a shoulder injury on top of everything else. Oh, cry me a river! And yes, I cry and sometimes that feels good, too.

Every morning, I open my eyes, see the mountains and the ocean and give thanks. I stretch and a few expletives come out of my mouth, but then I breathe. I am not alone. I allow myself to be inspired by beauty and kindness and joy as I build my armour and I try to focus on living every day.

Writing this has been one the most profound, difficult and cathartic exercises of my life.

COMING SOON! Mindfulness Based Cognitive Therapy – eight week session at BC Cancer–Vancouver Centre

This program, led by a counselor and a psychiatrist, seeks patients who are suffering from anxiety and/or depression and are interested in daily meditation as a means of living fuller lives. Efforts will be made to bring non-judgmental, kind and compassionate awareness to one's moment to moment experience as it unfolds. Mindfulness based practices will be combined with cognitive behavioral techniques to support patients living with a cancer diagnosis. You do not need to have experience with mindfulness based techniques to join this group.

If you suffer from anxiety and/or depression and are interested in joining this group, please ask your health care team for a referral by your Oncologist or Nurse Practitioner.

Relaxation therapy

By Tracy Stonehouse RSW, MSW Social Worker

ACK BY POPULAR DEMAND, the Relaxation Therapy program will resume drop in sessions at the BC Cancer Vancouver Centre. This goal of the program is to help patients develop personal strengths and resources for coping with the challenges of living with cancer. The skills learned during the program will provide an effective practice in stress-reduction, healing and health maintenance.

Relaxation therapy helps us learn how we can influence the autonomic nervous system. The autonomic nervous system (ANS) controls those bodily functions that occur without our effort. For example, your heart beat, blood pressure and digestion are controlled by the ANS and function without your conscious control.

The ANS has two main divisions. One part, the parasympathetic nervous system, helps the body function under normal conditions. The other part, the sympathetic nervous system, responds to stress. The ANS is very sensitive to complex cues from the body.

When we're faced with a very upsetting situation, such as a bear attack – or a brain tumour diagnosis - the sympathetic nervous system triggers a "fight or flight" response to stress. This response may include an increase in the rate of your heart beat or blood pressure and dilation of your pupils. These changes help you to fight against or run away from the stressor, but leave you feeling anxious and distressed.

In contrast to the sympathetic nervous system, the parasympathetic nervous system facilitates the return of your normal body functions. For example, it slows the heartrate, lowers the blood pressure and allows the normal digestive processes to occur. You can relax again.

We can influence the triggers that prompt the response of our ANS. A state of relaxation and calm can be reached through practicing guided mindfulness meditation, exercise, restorative yoga, yin yoga, massage, breathing meditation and any other activity that promotes calm and rest. When the relaxation response is evoked:

• muscle tension is released

- · heart rate slows
- blood pressure decreases
- the release of endorphins and other beneficial chemical substances is stimulated
- optimal immune system functioning is facilitated.

Coping with a brain tumour diagnosis and treatment promotes mental and emotional stress and anxiety. The above tools can also help reduce the risk of depression, anxiety and complicated grief/loss.

Relaxation Therapy sessions will take place beginning November 19, 2018 every Monday from 10 to 11:30 am in the John Jambor Room on the ground floor of the Vancouver Centre.

For other resources to help you cope with cancer see: www.bccancer.bc.ca/health-info/coping-with-cancer

For more information about the drop in Relaxation Therapy program at the Vancouver Centre, please contact the Patient and Family Counselling Office at 604 877 6000 x2194.

Medical Cannabis: What patients with cancer need to know

What is medical cannabis?

Medical cannabis, also known as medical marijuana, comes from the flowers, seeds and leaves of the cannabis plant.

- Cannabinoids are the chemicals in cannabis that can act as drugs.
- The two most familiar cannabinoids are tetra-hydrocannabinol (THC) and cannabidiol (CBD).
- The amount of THC and CBD in a cannabis product is responsible for most of its effects.
- It is important for you to know how much THC and CBD are in the product you are taking.
- There is no human clinical trial evidence that cannabinoids have any effect on cancer growth.

What is medical cannabis used for?

- Pain
- Nausea: queasy feeling or feeling sick to your stomach
- Anxiety: a feeling of worry, nervousness or, unease
- Insomnia: trouble falling asleep or staying asleep

How do I use cannabis?

Oils: this is the best form for cancer patients. It absorbs quickly in your mouth and does not smell.

Edibles (products you eat or swallow): cookies, teas, capsules or tinctures (drops).

Suppositories that you insert into your rectum (bum).

We do not recommend inhaling (smoking or vaping) cannabis. The smoke or gas may damage your lungs.



The story of the Brainiacs and the Ride to Conquer Cancer

By Paul Chapman

N 2008, FOUR GLIOBLASTOMA SURVIVORS who were members of the brain tumour support group decided to contribute to the effort for cancer research. They pulled in a few friends for a total of 8 cyclists on that original Brainiac team for the ride down to Seattle. The group raised \$39,955 for cancer research and so began the annual fundraising drive.



The team doubled again for the second year of the ride and created the first of our many Brainiacs jerseys compliments of Yaron Butterfield's artistic abilities.



The team hovered around 30 riders until 2013 at which time, it acquired a recruiter of new riders. Within 6 weeks after the 2012 ride, the recruiter had signed on over

100 new Brainiacs. Ultimately, 180 Brainiacs cycled that year and raised \$589,257 for cancer research.



In 2018, the ride destination moved to Hope B.C. and the team grew to 375 cyclists and raised \$688,458. The goal for 2019 is \$1 million!



After 10 years of the Ride to Conquer Cancer, the event has raised over \$96,000,000 for Cancer Research. The Brainiacs started with very few members, but are now one of the most respected teams and have raised \$2,355,981 in British Columbia alone. The Alberta chapter of the Brainiacs have raised an estimated \$400,000. This has been a wonderful experience in every way for the members of the Brainiac team!



After Day 1, August 25, 2018



Two of the four Brainiac founders, Paul Chapman & Yaron Butterfield, in 2013



At the front, two of the Brainiac founders, Jim Vanderhook (white shorts) and Paul Chapman (yellow flag)



A brain cancer patient starts putting hats on heads



Max Telzerow Photography

By Suzanne Heft

UT OF NOWHERE, my entire life changed immediately," remembers Andrew Taylor, who was diagnosed with a brain tumour in 2011. "Even though I tried to return to normal life, I knew things would never be the same."

There had been a seizure, then hospitalization, and many tests. A shocking diagnosis. At 41, Andrew was a successful energy lawyer with a wife, two young sons and a bright future; now he confronted a harsh reality — a brain tumour that could be treated but not cured. Over the last seven years, Andrew endured surgery, radiation, two years of chemotherapy, and numerous scans and blood-work, like many brain tumour patients. But what's different about Andrew is that he took that gruelling experience and channelled it into creating something for others.

So after leaving his law practice a year ago, Andrew shifted gears. He and his wife launched a charity called TOUGH S.O.B., which offers a unique way to comfort and support those in cancer treatment, by providing them with toques carrying a special 'hidden' message of empowerment and strength.

"A friend gave me a toque when I was sick," he explains. "He had embroidered the words 'TOUGH S.O.B.' on it. The toque meant a lot to me. It was warm and covered my bare head and my scars. I liked the idea of a reminder that I was

braver than I knew. But I didn't want to proclaim that idea to the world in such a brazen way," recalls Andrew, who lives in Toronto and is a patient at the Princess Margaret Cancer Centre. "I wore the hat for many years, but never in public."

Andrew made his own version of the toque with the words 'TOUGH S.O.B.' printed backwards, so only the wearer could see them in the mirror. "To the rest of the world, the words are cryptic and cool," says Andrew. This logo is printed across the brim of each toque.

"Medical treatment for brain cancer can be disfiguring and debilitating for many people. When you look in the mirror, sometimes you don't recognize the face looking back," he explains. "Our backwards logo is more than letters and words. It's a private reminder to the wearer that we are more than patients in a hospital gowns, more than statistics, more than symptoms

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For more information about how you can support enhanced patient care, patient information and brain tumour research, please contact Fatima Hassam, Associate Vice President, BC Cancer Foundation.

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and circumstances. TOUGH S.O.B. is a reminder that we are all strong, resilient and brave."

TOUGH S.O.B

"I want cancer patients to know what I did back then, and still do today: that you are stronger than you think," Andrew says. "And, you are not alone." In the last three months alone, the charity has made it possible to give free toques to over 1,000 cancer patients. The charity's website (www.toughsob.org) also has a growing section, called Stories of Courage, profiling people who are facing their future with bravery, dignity and resilience. Thanks to Andrew, their stories are inspiring philanthropy and community across Canada, one hat — and head — at a time.

Editions of *Headlines* are also available as a pdf download on our website at: www.bccancer.bc.ca/headlines

If you would like to submit an article, ask a question, or serve on our patient and family editorial board, please contact Rosemary Cashman at rcashman@bccancer.bc.ca or 604 877 6072 (phone) 604 877 6180 (fax).

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