

# Headlines

Spring 14

A newsletter for brain tumour patients and their families

## MY STORY

### Trick or Treat

By Margaret Ng

#### Trick: An unexpected guest

**O**CTOBER 31, 2013: Halloween morning I woke up with a sudden severe headache on the right side of my forehead with vomiting, nausea, and diarrhea. During a second visit to the hospital emergency department, a CT scan revealed a probable brain tumour. Was this a trick? Is this a nightmare?

Shocked, scared, angry, and in disbelief, I was admitted to the hospital for further investigation. On November 8, 2013, I had surgery to remove the tumour in my right temporal lobe. I was diagnosed later with a grade three oligoastrocytoma, a malignant form of brain cancer, and the prognosis wasn't good. In only a few short days my world came crashing down on me and my life was flipped upside down, spinning out of control. I spent that day crippled by sadness, crying with my family.

**Decision:** Later that day during a drive home from a break at the mall, I reflected on my sadness and my prognosis in silence and decided not to be sad anymore. I felt like being sad was no way to live the rest of my life. I thought to myself; whether I have days, months, years, or decades to live, I didn't want to spend my time left in this world being negative about my circumstance. I am not miserable. I am happy and loving life.

**Focus:** With my life spinning out of control

I quickly committed myself to learning and focusing on the things I can control. In addition to complying with conventional cancer treatments, I turned to evidence based practices known to support health and healing such as nutrition, exercise, sleep, stress management, and supplementation. To learn more about these integrated cancer care strategies and more, I joined *Inspire Health* and committed myself to doing what I can do to position myself to defy statistics, to be in the best state physically and mentally,

to heal and thrive. I am not condemned. I am in control and confident.

**Beliefs:** My religious beliefs helped me to accept my diagnosis and reflect on my belief that everything in life happens for a reason. I've always believed that in all life events, positive or negative, even with something as tragic as death, there is something to learn and something to gain either personally or for those around us. It may not make any sense at the time, and may seem unfair, but it is all part of

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Margaret (holding Cookie) and her husband Joseph (holding Mochi)

**Q** My doctor told me my disease is stable. What does this mean? Is this what they call remission? I still get seizures and have problems with my memory and feel tired all the time, so I can't go back to work. When will I feel like my old self again?

**A** Since this is three separate questions I will break them down individually.

1) Regarding the meaning of "stable disease," the term comes from how we assess disease response on imaging. When we look at the MRI, there are two possibilities: the patient has visible tumour remaining or there is no

clear sign of tumour. We compare the current scan to prior scans to determine how things have changed over time.

If there is *visible tumour* and it has increased in size, we call that *progressive disease*. If the tumour is unchanged in size, we call that *stable disease*. If it has decreased in size or disappeared, we call that a tumour *response to treatment*.

If the previous scan showed *no visible tumour*, there are only two possibilities: recurrence (the development of new visible tumour) or *stable disease* (no new evidence of tumour).

There are specific guidelines called the RANO (Radiologic Assessment in Neuro-Oncology) criteria

## Question + answer



that were developed by specialist neuroradiologists to guide the way we read scans in research settings. We use the RANO criteria when we look at scans in the clinic, too, but recognize that research criteria don't always fit every real life scenario, and that every case needs some degree of sound clinical judgement.

So basically when we say a scan is stable, it means it has not changed from prior scans or has changed only very minimally. For clinical trials, that means the tumour has grown or diminished by less than 25% of the prior scan's size. In clinical practice, sometimes 25% growth is large enough for us to say that the tumour has grown, especially if it is associated with increased symptoms.

2) Regarding the term *remission*, this is a medical term to indicate that the patient has no evidence of the underlying disease but does have a risk of recurrence, i.e. is not clearly cured. In some cancers, remissions of a certain duration are deemed to be a cure. That is rarely the case for brain tumours. Some patients will have had a complete resection of all visible disease and radiation and chemotherapy can kill most of the residual microscopic disease. If we see no evidence of tumour on subsequent imaging, we can call that a "*remission*," but accept that the risk of recurrence remains quite high.

3) Finally, the last question refers to the return to feeling like one's "old self." The brain is the most delicate and important organ in the body. It is who we are. A brain tumour changes things dramatically by infiltrating and damaging this delicate tissue and the important connections within the brain. Further injury can occur from surgery, radiation and even chemotherapy, leading to impaired functioning. The brain does have "*plasticity*" which means it can adapt to damage and improve in functioning, but it can never regenerate and repair itself like other tissues. The degree of brain plasticity depends on a number of factors, location of the damage and age of the patient being the most important ones. Typically recovery will take 6 to 24 months for brain injury of any type and is often incomplete

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*An evening of information & support*

## Art Therapy for those affected by a Brain Tumour



**When:**

**Thursday, April 24**

**6:30-8:30pm**

**Where:**

BC Cancer Agency  
Vancouver Centre  
John Jamber Room  
600 West 10th Avenue, Vancouver

**Who:**

Brain tumour patients & their loved ones

Nutritious refreshments will be served  
NO art experience necessary

**For more information call:**

**604.877.6000 x 672813**

This session will begin with a support group style check-in, followed by an art therapy session led by Dr. Cathie Dunlop, BC Cancer Agency art therapist. This will include:

- Information on art therapy as a restorative practice and a helpful tool in the cancer journey
- Facilitated group art-making activities (No previous art experience necessary)
- Suggestions about how to use art as therapy in your daily life

## First world summit of brain tumour patient advocates



Photo by Paolo Salcido, SalcidoArts, www.salcidoarts.com

By Kathy Oliver,  
Co-Director of the International  
Brain Tumour Alliance

**T**HE INTERNATIONAL BRAIN TUMOUR ALLIANCE (IBTA) is a worldwide alliance of brain tumour patient and caregiver organisations, clinicians, researchers, allied healthcare professionals and others involved in the field of brain tumours. Founded in 2005 in Edinburgh Scotland, IBTA advocates for equitable access to brain tumour therapies, enhanced support for those affected by brain tumours, advances in research into the cause and treatment of brain tumours and increased awareness about the challenges related to these devastating diseases.

The first World Summit of Brain Tumour Patient Advocates, organized by IBTA, took place November 19-20, 2013 in Lafayette, California. The Summit brought together

over 60 dedicated brain tumour patient advocates representing the main support, advocacy and information charities and not-for-profits from 20 countries around the globe. Attendance at the Summit was by invitation and participants came from Argentina, Australia, Belgium, Canada, Denmark, India, Ireland, Italy, Japan, Lithuania, Netherlands, New Zealand, Norway, Singapore, Spain, Sweden, Taiwan, United Kingdom, United States, and Zimbabwe. Invited Canadians included members of the Brain Tumour Foundation of Canada and the Canadian Alliance of Brain Tumour Organizations.

The conference was professionally facilitated and collegially designed so that nearly all of the participants presented in a plenary session, spoke as part of a panel, ran a workshop or marketplace, acted as rapporteurs or assisted in a practical way to ensure a smooth and fruitful meeting.

Meeting participants were able to exchange ideas about best practice and discuss some of their unique challenges and advocacy experiences in their own countries. For example, those attending from Zimbabwe described how their advocacy efforts typically focus on meeting the most basic human needs, such as provision of food, since treatment options are poor to non-existent. A profound appreciation for the experiences and hurdles of others around the world grew out of our shared time at the Summit. It is hoped that the insights and inspiration gained from our discussions will help organizations around the world to provide the best possible services to brain tumour patients and their families.

For further information about the IBTA, visit [www.theibta.org](http://www.theibta.org) or contact [chair@theibta.org](mailto:chair@theibta.org) or [kathy@theibta.org](mailto:kathy@theibta.org)

**Question + answer**  
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if certain critical structures are damaged or if the patient is an adult. So it's rare that a brain tumour patient will return to feeling the exact same way they felt before the disease struck, but improvement can continue for many months after treatment.

Seizures may remain a lifelong problem because of the scarring of the brain related to the tumour and its treatment. All brain injuries, whether related to tumours, trauma or stroke, are at risk of producing a seizure disorder. Fortunately for most patients, seizures can be effectively treated.

*Dr. Brian Thiessen, Neuro-oncologist*

For more information about your personal recovery from brain injury and response to treatment, speak to your health care team, or see: [www.bccancer.bc.ca/PPI/TypesofCancer/BrainCentralNervousSystem/default.htm#Coping](http://www.bccancer.bc.ca/PPI/TypesofCancer/BrainCentralNervousSystem/default.htm#Coping)

# SPRING sprint 2 0 1 4

## Brain Tumour Foundation of Canada Spring Sprint 2014

Walk or Fun-Run (2.5 km or 5 km) to fund research and provide education and support for brain tumour patients and their families.

Register online at [www.springsprint.ca/site/PageServer](http://www.springsprint.ca/site/PageServer) or call 1.800.265.5106 for more information.

Make your own special shirt or receive a white participant tee-shirt by registering online. *Blue shirts are reserved for survivors, orange shirts for volunteers.*

To check-in on the day of the sprint, please bring your completed donation forms and all cash and cheques you have collected. Cheques are made payable to **Brain Tumour Foundation of Canada**.

### Vancouver

- Date: **Sunday May 25, 2014**
- Location: Burnaby Lake Rugby Club
- Registration Opens: 10:00 am
- Walk/Run Begins: 11:00 am
- Event Wrap Up: 1:00 pm

### Victoria

- Date: **Sunday, May 25, 2014**
- Location: **NEW FOR 2014!**  
University of Victoria, Ring Road.  
Parking Lot #10
- Registration Opens: 9:30 am
- Walk/Run Begins: 11:00 am
- Event Wrap Up: 1:00 pm



*Trick or Treat  
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God's master plan. I am not afraid. I am receptive and optimistic.

**Opportunities:** Coincidentally or not, my dad had a benign brain tumour, which was discovered 20 years ago while I was a teen. Growing up I saw him struggle with his brain tumour as he went through repeat surgeries and treatment. He fell into depression, struggled with his faith and questioned God, Why me? The question I've always focused on and encouraged him to reflect on is rather, why not me? Because we have been selected and given a unique opportunity to experience and do something different in our life. We need to learn to embrace life's challenges and setbacks. To view them as opportunities for personal growth, and appreciate that we've been given the opportunity to refocus our energy and time on the things that truly matter. I am not lost. I have a new beginning and I am excited for the future.

### **Treat: An unexpected sweet treat**

Being diagnosed with brain cancer has been a transformational opportunity for me. A sweet treat disguised as a brain tumour. My unexpected guest has given me the opportunity to live my life with gratitude, do the things that I enjoy and love, and learn to do more of what I can do to keep my mind and body healthy and in balance. My health and fitness were admired and praised before this sweet treat. My hope is to continue to amaze people during my healing journey and to inspire others to take control of their health and healing. Even though I have brain cancer, I feel healthy and I am strong and positive.

This newsletter is published through the generous support of the BCCA Neuro-oncology Fund. For more information about how you can support enhanced patient care, patient information and brain tumour research, please contact Sharon Kennedy at the BC Cancer Foundation, 604 877 6160 or 1 888 906 2873 or [skennedy@bccancer.bc.ca](mailto:skennedy@bccancer.bc.ca)

Editions of *Headlines* are also available as a pdf download at:  
[www.bccancer.bc.ca/PPI/copingwithcancer/specifiresources/Neurooncology.htm](http://www.bccancer.bc.ca/PPI/copingwithcancer/specifiresources/Neurooncology.htm)

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](mailto:rcashman@bccancer.bc.ca) or 604 877 6072 (phone) 604 877 6180 (fax).

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