

Headlines

Summer 15

A newsletter for brain tumour patients and their families

MY STORY

Me, myself and my brainstem tumour: Memoirs of a pediatric brain cancer survivor

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By Bayan Azizi

I WAS FIRST DIAGNOSED with a life-threatening tumour in my brainstem in December 1998, just after my ninth birthday. My diagnosis was of no surprise to my family, considering all of the symptoms I had as a young child. Finally, after years of uncertainty, we found an answer to our concerns. At first we were all in deep denial about the news, but I for one learned to accept any situation that life threw at me and move forward regardless of any turmoil in my life.

I chose to write a book as a way of spreading my message of hope and perseverance to other families and patients who may be going through a situation like mine. I have two main messages that I attempt to convey in my book.

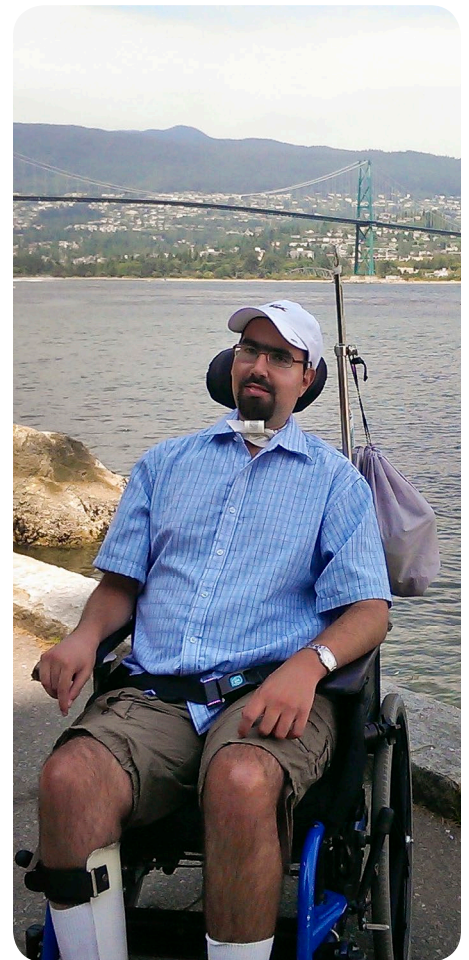
The first is never to give up. This is the one that defines me best and is my absolute favourite. Having the determination and will to survive got me a lot further in life than some might

have expected. My treatment included three brain surgeries, multiple rounds of chemotherapy, maximum radiotherapy and the removal of two vertebrae in my neck. Afterwards I required extensive physiotherapy to regain the strength in my neck and learn to walk and stand again. The odds were against me, and it would have been completely understandable if I had given up on myself. But this was the exact opposite of what I wanted to do with my life, and I refused to allow anything to impose on my self determination.

And that is my second message: don't limit yourself. Despite the many side effects I've experienced, I have not let them take over my life. I always set high goals for myself and have remained determined to achieve my goals. After all, I believe that you must persevere if you really want something in life.

I hope my book will inspire people not to give up on themselves no matter what the odds may be.

Available through your local or online bookstores.



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For more information about how you can support enhanced patient care, patient information and brain tumour research, please contact Erik Dierks, Vice President, Development at the BC Cancer Foundation TOLL FREE at 1 888 906 2873 or by email at erik.dierks@bccancer.bc.ca

American Society of Clinical Oncology meeting (ASCO) 2015

By Dr. Brian Thiessen, Neuro-oncologist

THE WORLD'S LARGEST annual cancer conference was held in May in Chicago. There was much excitement about new immunotherapies being developed for many cancers including brain tumours. As a result, the organizers had a separate symposium just to discuss some of the best work in immunotherapy for malignant gliomas. Although the three studies presented were quite new and could only offer preliminary results, it was exciting nonetheless.

There are three major ways scientists are working to activate the body's immune system against brain tumour cells. First, vaccines are being developed both against known brain tumour proteins (like EGFRvIII) and against proteins derived from the patient's own tumour (like dendritic cell vaccines). Second, specific viruses, termed oncolytic viruses, are directed to attack tumour cells causing them to rupture, die and release their proteins to the immune system. And finally, immune "checkpoint inhibitors" prevent the normal shutdown process within the immune system so that it remains activated and can continue to defend against tumour cells. This third approach is still in early phases in brain tumours, and there were no study results available yet for presentation.

We did see the results of a phase II study of an EGFRvIII vaccine in relapsed glioblastoma. The survivals were compared to patients receiving a placebo, or dummy vaccine. There was a two month improvement in overall survival favouring the active vaccine, but

the numbers of patients were too small to really determine how meaningful that improvement was. The BC Cancer Agency recently participated in a phase III trial with this vaccine; once the final results are known we'll have a better idea how well this vaccine works.

There was also a phase II trial of an oncolytic virus given to patients with glioblastoma prior to their radiation and chemotherapy. These patients were compared to patients that received only radiation and chemotherapy for glioblastoma. In this trial the virus improved survival by four months, but again there were not many patients enrolled and there was no randomization, so results need to be interpreted with caution. Nonetheless, study findings were encouraging and further clinical trials using this treatment are planned.

During the main platform session for brain tumours at ASCO, the only big phase III trial presented was the Novo-TTF trial in glioblastoma. Novo-TTF is a device that delivers electromagnetic frequencies to the brain through transducers attached to the scalp and hooked up to a battery pack worn in a backpack or plugged into a wall outlet. The units are worn for twenty hours daily. Seven hundred clinical trial patients with newly diagnosed glioblastoma were randomized to receive radiation and chemotherapy with or without the Novo-TTF device. Overall survival was improved by three months for those who used the Novo-TTF device. The data still need to mature to see if the results remain consistent as more time passes, but for now Novo-TTF does seem to offer a modest survival benefit in this disease.

Unfortunately, the device is unwieldy in its current form and prohibitively expensive (\$20,000 USD/month). As such, it likely will not be adopted worldwide as a standard of care for this disease.

Finally, there were two papers demonstrating the new molecular classification of grade II and III gliomas. Previously we separated these tumours by their appearance under the microscope into low grade oligodendroglioma, low grade astrocytoma, anaplastic oligodendroglioma and anaplastic astrocytoma. Now with molecular genetic techniques we can split these tumours into subtypes that give us an even better idea regarding prognosis. Tumours with isocitrate dehydrogenase (IDH) mutation and 1p/19q chromosome deletion represent the best prognostic group. Tumours with IDH mutation but no 1p/19q chromosome loss are an intermediate prognostic group, and tumours with normal IDH have the worst outcome, often behaving like a glioblastoma (grade IV tumour). We are fortunate at the BCCA to be able to test for these markers and thus design more personalized treatment plans based on genetic subtypes of tumours.

Stay tuned for next year's update where we should see results from a number of phase III trials and possibly some phase II work with immune checkpoint inhibitors and poliovirus.

For more information about clinical trials, see the Health Canada website: www.hc-sc.gc.ca/hl-vs/iyh-vsv/med/clinical_trials-essais_cliniques-eng.php

Also: www.bccancer.bc.ca/our-research/participate/clinical-trials

Editions of *Headlines* are also available as a pdf download on our website at:

www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/brain-central-nervous-system/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).

All content by Rosemary Cashman unless otherwise specified.



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

The Terry Kennerley Award

for contributing to the Brain Tumour Community



Now is your chance to recognize an individual who has made living with a brain tumour a little easier, a little more hopeful, and a little less lonely, for example by:

- Supporting other patients/families
- Promoting public awareness about brain tumours
- Improving health care delivery, or
- Contributing to research

Deadline for Nominations:
September 1, 2015

Terry Kennerley's experience with a brain tumour made him all the more committed to helping others with this disease. He was a source of hope, support, strength and good humour to patients and health care professionals alike. It is in memory of his generous spirit that this award is established.

To nominate, please include:

- 1) The name of the person you are nominating
- 2) A short paragraph explaining why you are nominating this person
- 3) Your name and contact information

(BCCA staff are excluded from receiving this award)

For more information about the Terry Kennerley Award see the BCCA webpage:

www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/brain-central-nervous-system/terry-kennerley-award

or ask your health care providers



Send nominations to:

Rosemary Cashman
rcashman@bccancer.bc.ca
604.877.6072

InspireHealth Supportive Cancer Care Services

By Mark Fernandes,
InspireHealth Marketing and
Communications Manager

INSPIREHEALTH is a not-for-profit organization funded in part by the BC Ministry of Health. Our care team is composed of family physicians, nutritionists, exercise therapists, clinical counsellors and other allied health professionals. At InspireHealth, cancer patients are offered an opportunity to consider ways to improve their physical, spiritual and psychological well-being. Patients are encouraged to create an individualized plan that improves their health in multiple areas such as nutrition, exercise, sleep, stress reduction, healthy communication and rekindling passion and joy in living.

Patients can engage with InspireHealth before, during and after standard cancer treatments. No medical referral is required. There is no charge for InspireHealth services if you are a Canadian resident with a cancer diagnosis, or if you are the cancer patient's chosen support person.

InspireHealth has centres in Vancouver, Victoria, Kelowna, and also the virtual centre InspireLIFE Canada. Membership includes options for individual consultations with a medical doctor, nutritionist, exercise therapist and clinical counsellor. Classes include cooking, yoga, exercise

and fitness, relaxation and meditation, small group discussions, laughter yoga, and acupuncture.

InspireHealth also offers online programs and telephone appointments for

patients living far from the InspireHealth centres.

For more information call us at 1-888-734-7125 or visit www.inspirehealth.ca.



InspireHealth
SUPPORTIVE CANCER CARE

CALL TO ARTISTS Brain Tumour Awareness Month

ART EXHIBIT | OCTOBER 7-13, 2015

To mark Brain Tumour Awareness Month and to showcase the remarkable creativity of the brain tumour community, the Patient Family Advisory Council of the BC Cancer Agency, in partnership with the Visual Space Gallery, invites art submissions by **anyone** affected by a brain tumour.

Brain tumours affect a diverse group of people: patients, families, friends, care providers, men, women and children of all ages.

*Please email bcgmtART@gmail.com by **July 31**, with an expression of intent to submit your work(s) of art including the following criteria:

1. Name
2. Email
3. Telephone
4. Art medium (All artistic media considered. Maximum dimensions = 3ft x 3ft.)
5. A short statement explaining how you've been affected by a brain tumour.

***FINAL SUBMISSION DUE: SEPTEMBER 10, 2015**

Please note: Pieces will be selected via a jury process. Selected artwork will be included in a public exhibition.
Works of art must be install ready.

Brain Cancer Got Me Thinking