

Headlines

Summer 17

A newsletter for brain tumour patients and their families

MY STORY

What I learned from cancer

By Dave Abbott

IN SEPTEMBER 2014 I was diagnosed with an inoperable brain tumour – a brainstem glioma, aggressive and terminal. I was given 3 to 12 months to live. Needless to say I was in shock. I remember walking the corridors of Lions Gate Hospital with a physiotherapist on each side of me, a wide belt wrapped around my waist, a physiotherapist hanging on to the belt. I was hanging on to a walker dragging my right foot. The tumour is on the left side of the back of my skull affecting the right side of my body. I had lost some muscle mass in my right arm and leg. The tumour also affects my vision pathways so that I experience sporadic double vision.

I received radiotherapy in October 2014. The tumour shrunk a bit, then started to grow again. My only other option was chemotherapy.

For the first 6 months of chemo I had no side effects whatsoever, but from the 7th month on I felt tired. But I am now walking – unaided – no walker, no cane. I completed chemotherapy in November, 2016 and the tumour had reduced in size by about 85%.



I have intentionally lost 70 pounds. I used to weigh 223 pounds – I was officially obese, and my blood pressure was high – 180/100. I used to snack on cookies, cake or chips every single night for over 30 years. I stopped doing that well over two years ago.

I am now in the normal weight range for my height and my blood pressure is also in the normal range.

What has cancer given me?

I now believe that I have to accept the cancer and include it in my life. What are the lessons in having this cancer? I believe that it's here for a reason, and I choose not to feel like a victim and instead focus

on restoring my sense of personal power. I believe that I am more powerful than the cancer.

In accepting the cancer, I have also tried to find balance in my life. What is out of balance in my life? Given that I am a physical, mental, emotional and spiritual being, I try to give attention to all of these aspects of myself and address any areas that need support.

I also try to focus on doing the things I love as this promotes a healthy self esteem. I am

a recording artist and currently recording original music on guitar with my best friend of 35 years. Music is my first passion. My second passion is writing and teaching. I am working on a fictional short story tentatively called *Evolving* with the second one titled *Evolved*.

The bottom line? I am choosing life by doing what I love to do. I was told I had 3 to 12 months to live and that was almost 3 years ago.

I will continue to be in charge of my health and my life.

For more My Story features see the index of articles at <http://www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/headlines>

American Society of Clinical Oncology (ASCO) 2017

By Dr. Brian Thiessen,
Neuro-oncologist, Vancouver Centre

IT'S JUNE. IT'S CHICAGO. It's ASCO 2017.

The world's largest cancer meeting once again brought together leading investigators in oncology to present their findings from hundreds of clinical trials including several key studies in brain tumours. As usual there was a mix of good and bad, but in all cases we gained new information to lead further cancer research.

Starting with the bad news, there



were two randomized trials in relapsed glioblastoma and one trial in relapsed grade 3 gliomas that showed negative results, meaning that the experimental treatment was not more effective than our current therapies for those patients whose tumours progress after initial treatment.

The Checkmate 143 trial in relapsed glioblastoma compared nivolumab (an anti-PD1 antibody, also known as an immune checkpoint inhibitor, which is a type of immunotherapy) to bevacizumab (an anti-

VEGF antibody, also known as an anti-angiogenic agent). Bevacizumab has been used frequently in relapsed glioblastoma so it was used as the standard treatment arm and the nivolumab was the experimental treatment arm. In this study there was no difference in overall outcome for patients who received nivolumab and patients actually had relatively delayed progression of the disease when they received bevacizumab.

There was also a smaller randomized study with a peptide vaccine comparing it to physician's choice of treatment at relapse in glioblastoma. The vaccine was

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Brain Cancer Got Me Thinking Art Show 2017

By Yaron Butterfield

THE PATIENT AND FAMILY ADVISORY COUNCIL (PFAC) hosted our second Brain Cancer Got Me Thinking Art Show to celebrate Brain Tumour Awareness Month in May. The Visual Space Gallery generously allowed us to hold the exhibition in the gallery from May 3-9, 2017. Individuals affected by a brain tumour diagnosis submitted works of art in various media, and over 30 pieces were selected by a jury for the exhibition. Each work of art was accompanied by the artist's biographical statement, providing a vivid impression of the effect of this diagnosis on an individual and his or her community.

The opening night event on May 3 celebrated the artists, who included patients, family caregivers, health care professionals, adults and children.



For more information and photos see www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/art-show





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 15, 2017

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:

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rcashman@bccancer.bc.ca
604.877.6072

ASCO 2017

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designed to sensitize the body's immune system against glioblastoma. Again there was no difference in outcome for overall survival for patients receiving the standard treatment or the peptide vaccine.

The TAVERAC trial in recurrent grade 2 and 3 astrocytomas compared temozolomide vs. temozolomide with bevacizumab. The study results showed no improvement in overall survival with the addition of the anti-angiogenic drug bevacizumab. Similarly, quality of life and cognitive outcomes were no different. This result isn't terribly surprising given the lack of aggressive angiogenesis (blood vessel production) seen in lower grade gliomas compared to glioblastoma.

As for the good news at the meeting, there were a couple of interesting

clinical trials in rare gliomas. A study with vemurafenib (an inhibitor of BRAF) in gliomas that were positive for the BRAFv600E mutation showed significant activity for this agent. This was especially true for pleomorphic xanthoastrocytomas (PXA's), a rare type of low grade glioma. Six of seven patients treated with this agent showed significant tumour regression. Given this tumor rarely, if ever responds to traditional chemotherapy agents, this was quite an exciting result.

Meningioma is another brain tumour that has shown little if any tendency to respond to chemotherapy agents. A phase 2 trial of octreotide (an endocrine hormone) and everolimus (an mTOR inhibitor) combined in relapsed meningioma showed some potentially good results. Both drugs have been studied individually with minimal

effectiveness, but the combination seems to work well. About 25% of the tumours treated showed shrinkage with this combination whereas in past meningioma studies with various other drugs, less than 5% showed any reduction in tumour size.

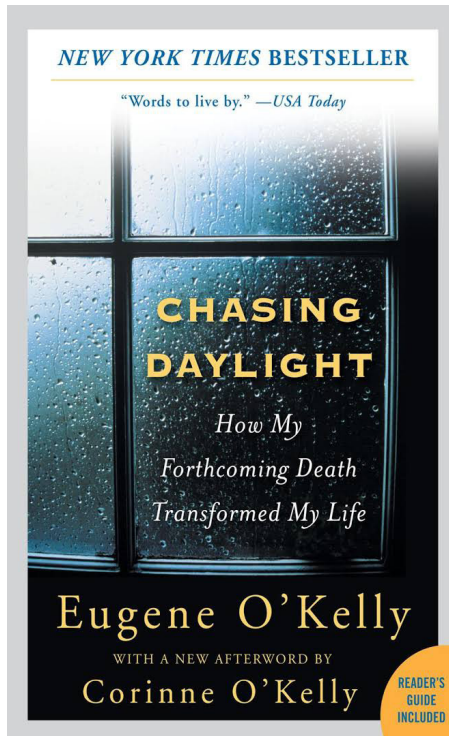
So in the end it was nice to see some less common tumours investigated with some early positive results. It was disappointing to see immunotherapies fail to make a difference in relapsed glioblastoma. Hopefully the immunotherapy trials in newly diagnosed glioblastoma will show better results. Additionally it may be important to look at combination immunotherapies such as vaccines plus checkpoint inhibitors to see whether a more aggressive immunotherapy approach is useful.

ASCO presentation abstracts are available at <http://abstracts.asco.org/>

Chasing Daylight by Eugene O'Kelly

By Yaron Butterfield

AFTER MY DIAGNOSIS with a glioblastoma in 2004, it was tough when I had to leave my work as



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 Publisher: McGraw-Hill Education;
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<https://www.amazon.ca/Chasing-Daylight-Forthcoming-Death-Transformed/dp/0071499938>

a cancer researcher. Big changes were happening in the DNA sequencing world so I continued to attend various seminars and meetings. In one such meeting in 2006, while in the middle of treatment after the recurrence of the cancer, I was approached by a UBC professor who had collaborated with my team. He had heard what I had been through. After we chatted for a bit, he said he had something for me and asked me to wait. He rushed out of the auditorium and about twenty minutes later returned with a book in his hand. He gave it to me and said that it had been a great source of inspiration for him. I read the book, entitled *Chasing Daylight*, with keen interest.

This inspirational memoir by a CEO of a large accounting firm, tells of his diagnosis with the same cancer that I have. He said he felt blessed with what happened to him despite being told he didn't have long to live. He took advantage of every moment to enjoy the life he had left, embracing relationships with family and friends. I could relate to many of his experiences, even though I was not a wealthy businessman running a successful company. He feared not being around for his children as they grew up, even as I feared not having children at all. His views on life and what's important was shifted by his new diagnosis, just as mine were. I continued to read with the hope of seeing how he went back to work, or how he took on new endeavours.

That was not to be.

I had flipped ahead to the last chapter and saw that it was written by his wife. My heart sank, but I continued to read the book to the end. With each month, his health declined but his spirit did not. Eventually he was no longer able to write and his wife took over. The subtitle of the book, *How My Forthcoming Death Transformed My Life*, was very appropriate, with his wife writing the last chapter about how "you come to understand strength, commitment, love, and most importantly, life, in a way that humbles you."

Was I naïvely thinking that I would be fine having been diagnosed with the same cancer as the author, a glioblastoma (GBM)? Did the professor give me the book knowing that most likely I should be considering my forthcoming death?

What this account did was to help me realize that I am not alone in the fight. It showed me that even with a cancer diagnosis, we can choose how to react to adversity and live our lives – and live happily. I continue to benefit from the author's example, even as he lived his final days.

A copy of this book is available to borrow from the BCCA Library. For more books about living with a brain tumour, please see the BCCA Library's Pathfinders at <http://www.bccancer.bc.ca/our-services/services/library>

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www.bccancer.bc.ca/health-info/types-of-cancer/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).

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