

SURVIVOR STORY #11: YARON BUTTERFIELD

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The beginning of 2004 kicked off as a new stage in my life. I had survived the breakup of a 4-year relationship and was ready to move forward. Work was going well and I hoped to move up in my career as a cancer genomics scientist; just 10 months earlier in April 2003, I played a large role in the analysis of the SARS coronavirus genome that made world-wide headlines after we announced our accomplishment. Life was busy with my work and I balanced it out with taekwondo, yoga, art, and my love of ice hockey.

On a Monday morning, February 23, 2004, a day and a half after I had scored 5 goals in the best hockey game of my life, I collapsed in a grand-mal seizure and was subsequently diagnosed with glioblastoma and was given a prognosis of living 12 to 18 months.

Analysis also showed that I had the IDH1 mutation of interest and that MGMT was methylated—both good in my case. I decided to follow any treatment plan that was laid before me. The tumour was deemed to be too deep for surgery, so I went ahead with chemotherapy (temozolomide or “TMZ”) and radiation.

I focused my emotions and energy on the events of the day without really looking forward. I absorbed the beauty around me, the flowers and trees, the fresh air, even the grocery cashier lady. Friends and family, including my twin brother were there for me 24/7. Rather than rushing to work in the morning and then in the evening to do whatever I had planned, I had a lot of time to think. All my thoughts were directed towards my healing.

Unfortunately, in my third week of treatment, my white blood cells count dropped dramatically so I had to stop chemo and get blood transfusions. I continued with radiation and a couple weeks after it was done, we tried to see if I could handle the chemo but it immediately had an effect on my blood count so treatment was over.

It was time to wait, to see the results of treatment which would be a few months as they wanted to avoid any misinterpretation from possible pseudoprogression. I decided I wasn't going to let my cancer diagnosis and devastating prognosis rule my life. I also realized that life was too short, whether with cancer or not. And so I signed up on a dating website and soon after met someone. We went on a date a week after my

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birthday in July when I turned 30. I warned her about my recent diagnosis and that I hadn't even got results of treatment at that point. She said she wanted to stick around and see how things go, that she saw a fighting spirit in me. We started to date and with her being a big part of my thoughts and energy, I had little time to worry about the cancer. A few months later, the MRI results indicated that the tumour had shrunk.

It felt like a new future was unfolding in front of me. My girlfriend moved in with me, I started fundraising and training for a run, and I became a student again registering for courses in immunology and in bioethics at the local university. My fundraising led to the opportunity to do a marathon in Iceland. I used to be quite a runner and had done many half-marathons but I thought I'd see if I could do a full one.

That August of 2005, I completed the 42km run on the volcanic island and then traveled inland with friends. One night we sat in the hills of Vik, taking in the beautiful Northern Lights, and I felt that I was as far away as can be from the cancer and all that came with it. I had left the tumour behind; I imagined hoping it would never return. But it did. An MRI a couple months after I got back home showed that the tumour increased to double the size. I had to consider further treatment. TMZ is often less successful after recurrence as the new tumour is usually genetically very different from the first tumour. Any cells resistant to TMZ in the first treatment have now multiplied into a new mass. Given that, I was offered a clinical trial drug in November.

Once again, while I subjected my brain to more drugs, I was excited, preparing to getting married at the end of the year. During the ceremony my alarm went to reminded me to take the chemo. That night, I got sick which was a common thing for me since starting the new medication. An MRI in early 2006 showed the tumour had not shrunk. A decision was made to attempt TMZ again. Keeping in mind that I had showed much sensitivity to the drug when I took it before, the thought was that taking it one week per month would be tolerated. Also, I had not initially completed a full round treatment of the chemo; there could still be cancer cells sensitive to the drug.

This was my treatment for first 8 months of 2006 and thankfully by the Fall of that year, the MRI showed that the tumour has shrunk significantly. Around that time, I returned to my hockey team but now, instead of being one of the best players on the team, I was the worst. I also went back to my job at BC Cancer, thrilled to be back to the research, working with colleagues and making discoveries to help lead to more understanding on how to treat cancer. I managed to get involved in various research studies about

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brain cancer. One such project I was heavily involved in was the analysis of tumour profiles from patients with oligodendroglioma where we identified key interactions with a couple genes of interest and chromosomal alterations (e.g., CIC, IDH, 1p/19q). I also contributed to one of the first research projects <https://www.google.com/?client=safari> demonstrating the benefits of personalized oncogenomics.

In 2008, my daughter was born and she gave me even more motivation to stay healthy and strong. I wanted to give back to the brain cancer community and became coordinator of Canada's Brain Tumour foundation (BTFC) walk/run in Vancouver which I did for 7 years. In 2015 BTFC handed me the David Kelley Award for Community Service. At the ceremony after the award was presented, my daughter came to me and quietly asked, "You had cancer daddy?" I gave her a big hug, held back tears, and told her yes, but not to worry, it was gone.

With my knees a little compromised with all my running, I started to get involved in biking. In 2009, three other brain cancer survivors and I created a team we called the Brainiacs to help fundraise for cancer research leading to a 200km ride over two days every August. Over the years, our team has recruited many each with their own story, and we have raised millions of dollars.

I had graduated over the years from MRIs every three months, to every six and then once a year. Time was moving farther and farther away from my personal cancer experience. Perhaps it was gone but the side effects lingered. In 2014, during a hockey game, I sensed something strange. By the third period, I seemed to be seeing double and my brother drove me home. We were worried that I had experienced a seizure, but it was found that I was getting double vision because of damage to an optical nerve. This wasn't the first long term effect of radiation I experienced; my hearing on the left side of my brain around where the tumour had been, was also compromised. I attempted to continue to play but problems with my vision led to a few bad falls and a couple concussions as a result.

In the Spring of 2016, one morning with my daughter, I had trouble with my balance while walking and fell into the wall. I knew something was wrong and tried to call my brother but couldn't hit the right numbers. My daughter, now 8, called him and then 911 and before I knew it, I was at the hospital and by evening my voice was gradually returning. The next day, I felt much better and was told that I had a seizure. Thankfully, the incident was not a sign that the cancer was back but that my anti-seizure medication

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was too low. I recovered fairly quickly physically, but cognitively; the seizure affected me such that I had trouble doing the detailed tasks of analyzing sequenced cancer genomes. In January 2017, I had to take a break from work.

A couple eye surgeries to try and fix the double vision were not very successful but over time, things improved slightly. After a 2-week trip to Peru with other cancer survivors in November 2019, which included a great day on Machu Picchu, I felt ready to consider returning to work. However, in the Spring of 2020, I had another seizure. Staff at the hospital initially thought I had a stroke but soon realized that there was a blood leak between my brain and the skull: a subdural hematoma. This was another long-term effect of the radiation I had in 2004. One night at the hospital, I woke up and realized I could not move the right side of my body at all. After a surgery, I spent most of the rest of the year in physical and cognitive rehab. Since then, I have been trying to heal in various ways: continuing to exercise with biking and hiking, exploring yoga, tai chi, and qi gong, reading, writing and doing my art. I hope soon I will be ready to return to work and contribute to continued cancer research.

At this point in 2022, it's been over 18 years since my diagnosis of GBM. MRI's have been clear since the Fall of 2006. I am slowly getting my memoir together with the hope readers will be inspired and see that you can move forward past a devastating diagnosis and enjoy the world in your own way. I intend to continue doing that.

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