

Why not me?

By Lynda Tse

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WHY am I still alive when others are not?

In March 2006 my world was turned upside down when I was diagnosed with a glioblastoma multiforme (GBM), a type of malignant brain tumour. As a wife and mother of two young children, then aged 10 and 13, I was shocked and devastated. The statistics told me I had little more than a year to live. My oncologist told me, hand on heart, that he could not cure me.

Yet here I am, eight years later, still alive and living a full life. I love spending time with my family and friends, and immersing myself in my crafts and hobbies. I am back working as a kindergarten teacher, and my husband and I are making plans for the future.

I feel very lucky to be sitting here writing this. However my feelings of good fortune are sometimes tempered with what I call "survivor guilt".

Since my diagnosis I have met some wonderful people who have sadly succumbed to this disease. Why have I survived when they have not?

I have looked into the eyes of parents who have lost their children to brain tumours and grieved for them. It is not the way it should be.

Michael, my husband's first cousin was diagnosed with a GBM a few months prior to me. By the time I was diagnosed, Michael was already well into his treatment. He became my "go to" person. He introduced me to a brain tumour support group. This support group was held at the Wellington branch of the Cancer Society once a fortnight. This was very helpful for my husband and me as we began to navigate our way through this new and scary world of brain tumours.

Michael and I would chat on the phone, compare visits to our oncologist and meet for coffee. We were a team. I referred to us as the "Brain Tumour Warriors." When Michael's tumour recurred I was devastated.



Above: Lynda Tse (2nd from left), an eight year survivor of a glioblastoma, is pictured with her family in New Zealand (from left to right): son Nathan, husband and IBTA advisor Chris Tse, and daughter Cassandra

I visited him at home where he was under palliative care.

On one occasion I baked the family a plate of chocolate chip cookies. The next time I visited, Anne, his mum, told me that Michael said he had dreamed of the chocolate chip cookies, which made me feel that I had helped in some small way.

After Michael passed away, I found it hard to look into the eyes of Anne, a grieving mother, and not imagine that she would be thinking: "How come Lynda lives and Michael doesn't?" Even to this day I still find meeting Michael's family difficult.

Through the Cancer Society I have become a mentor for newly diagnosed brain tumour patients seeking support as they embark on their treatment. Sometimes we meet for lunch or coffee, otherwise we keep in contact by phone or email. I share my experience with them and hope that my positive, never-give-up attitude buoys them into feeling that they too will be a long term survivor.

Despite this positive thinking and fighting attitude, all too often the person's health

takes a turn for the worse. I then feel as though my good health is like rubbing salt into their wound. I feel their disappointment, their sorrow - like a boulder in the chest - and I am powerless to help change their situation.

Sometimes I feel unworthy of having this second chance at life. I didn't suddenly become a different person. I didn't suddenly become a saint, give up eating chocolate or become a person who never gets frustrated or annoyed.

I still get frustrated in bad traffic. I still get bothered by rude people. I thought by facing my own mortality I would become a better, more tolerant person able to transcend the trivial and petty annoyances of everyday life. I have met others with this disease who seem to have accomplished this. I am inspired by them.

In November 2013, I attended the inaugural World Summit of Brain Tumour Patient Advocates in Lafayette, California. I had initially not wanted to attend the conference, fearing my presence could make others feel uncomfortable. However the hope of meeting

other survivors, and the opportunity to learn about new treatments from elsewhere in the world, convinced me to go.

During the conference I met many people who had lost someone close to them from a brain tumour. I found it deeply moving when they shared their stories or talked of their loved ones. I remember thinking to myself: "I hope they don't mind me being here", so I kept a low profile until we all had to introduce ourselves.

When I was introduced as an almost eight year survivor of GBM, the room erupted into applause and there was nowhere to hide. I felt embarrassed but at the same time overwhelmed with the support and encouragement of everyone in the room.

At that moment, there was no place for feelings of survivor guilt, just a sense of sharing a difficult journey with friends who understood.

I try not to spend too much time in the land of brain tumours. I am grateful to be alive and I want to make the most of every day. I have come to realise that my feelings of survivor guilt are natural and I am determined not to let them affect my compassion towards others who are on this journey too. ■

ABTA's Breakthrough for Brain Tumors 5K Run & Walk



In 2013, the American Brain Tumor Association's Breakthrough for Brain Tumors 5K Run & Walk brought together over 6,200 brain tumor patients, caregivers, health care professionals, friends and family in seven cities across

the United States. Funds raised support the ABTA's brain tumor research funding program, as well as support and education programs for all tumor types and all age groups. Visit www.bt5k.org to learn more. ■



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