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**The only national Australian organisation
for the brain tumour patient, family and
caregiver.**



21st February 2009

Dear *Brain Tumour Alliance Australia* Supporter; a call to action against brain tumours.

If people could recover to tell others of their suffering, the problem of advocacy for people with malignant brain tumours would solve itself. Carers and survivors of the more benign forms of the disease are therefore left with a unique responsibility. They have seen the suffering caused by this disease first-hand.

A problem with brain tumours is the disease itself is so disturbing, so daunting, that many with a choice turn their attention away from it at the earliest opportunity. I fit that category for most of my illness from a benign brain tumour. I never wanted to be thought of as a 'brain tumour sufferer', 'person living with a brain tumour', and especially not a 'young person living with a brain tumour'.

After an incident at a former workplace two years ago, I now know that to reveal my condition to colleagues is to invite distrust, even ridicule. Twenty minutes after telling a colleague about my medical history, my former boss was standing in front of me, demanding to know why I had not revealed this information in the interview. '*Why had I lied?*' They never trusted my work again; never believed my answers to their questions, assumed that any problems in a project with even a tangential link to me were my fault.

And yet, I was compelled to return time and time again to speak out over my experience with brain tumours, to lend my voice to others when they say, 'this disease is different, this disease will challenge your sense of 'self''. Make you reappraise what it means to be you. Can you trust that emotion you are feeling right now, or is it merely the effect of the tumour? Your sense of time can be warped, and whole passages of your life may disappear. What happened the last week, the last month, the last few years?' 'Was it always this way, you wonder, am I becoming paranoid from my illness?'

In 2001, I was 19 and had just been diagnosed with a 6 cm³ pilocytic astrocytoma of the third ventricle. Massive hydrocephalus was causing my face to swell, my speech to become slow and slurred, and eventually, caused blinding headaches every morning which I put up with for weeks before going to a doctor. I was constantly forgetting important information as a result of my fornices between the thalamus and hippocampus being severely damaged. I could feel neither sad nor happy as my hypothalamus and other limbic structures were so compromised. Later I was told I could easily have died at any point. The diagnosis was a fitting tribute to the worst two years of my life to date. I had lost my friends, my family were angry at me, and everyone assumed I had gone mad. Things improved dramatically for me after this point.

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After I received my first set of pathology results, my neurosurgeon told me I was ‘very lucky’. I had one the most benign brain tumours, a pilocytic astrocytoma¹. After hearing condolences, and receiving sympathetic gestures for the last month from people around me, I had just learnt a staggering truth. All that I had been through over the past six or more years while the tumour expanded in my brain, while horrible, was far less worse than what the overwhelming majority of people with brain tumours will experience.

An entirely different fate may have befallen me. I may have been told, ‘I am sorry. It is a malignant tumour’. I may have even been told, ‘we are very sorry, there is little more we can do for you. It is a glioblastoma multiforme, grade IV’. I would be given a prognosis of around 6 months to one year. I may still be told these words. Benign tumours can turn malignant over time. With my history of a benign brain tumour, I remain far more likely than the average person to be diagnosed with such a malignancy.

Like many newspaper readers, my favourite journalist for many years was Matt Price. I raise his name reluctantly and with apologies to his family and friends, as he has only recently passed away, and his life was so much more than his final months. And yet, it is for this reason that his is an obvious demonstration that life is so much more than illness, this cause for its end. When readers learnt Matt Price was ill, thousands left messages on his blog wishing him a speedy recovery. They wanted him to return to write in his inimitable style that made the dry subject of politics enjoyable. They enjoyed his ability to capture the character of political players with a few apt quotes and commentary. They were shocked that he had cancer at such a young age, that his illness progressed so fast, that within months he had died. It was senseless. It was unfair. It was so unlikely.

Matt Price said of his illness,

“No pithy punchline, just the obvious observation - life is fragile, hug your loved ones.”

This disease of the mind took away the life of a young father and husband, one of our best and brightest in his prime, for no apparent reason. This senseless loss continues every day. Survivors may feel they suffered a form of death. That their old ‘self’ was replaced by a poor impersonator.

The fragility of the mind continues to be unappreciated.

How are we to help people diagnosed with this disease? We know of no preventable risk factors such as lifestyle. We cannot advocate screening programs because that is impractical.

At this point, many understandably turn away from the disease, which takes so much and offers so little, even in the manner by which it takes a persons’ life.

I remember feeling angry in the weeks before my first surgery. As a pessimist, I was expecting to die, and after two years of anhedonia-turned-depression, shame, and failure, I was simply relieved there was a cause for my current state; that I wasn’t meant to be like this. I was however angry at being denied the capacity to comprehend my life in the final days I thought I had left. Angry that I was being denied the mental state to fully reflect on the significance of my passing. No one wants to die but death from a brain tumour ranks among the most undesirable ways if one was given the choice. Suffering caused at every stage between diagnosis and death from a brain tumour remains open to our intervention. It is a horrible disease, but we can all act in ways to reduce its impact.

¹ The former word means to grow in a ball-like cyst, the latter word describes the cell type it originated from, the astrocyte, a small, common cell in the nervous system.

BTAA believes it can help people with brain tumours, and those who will be diagnosed, through:

1. Advocating for improved treatment facilities, services, and health care funding.
2. Helping patients and their loved ones understand their disease, and ways they can help reduce its burden on their lives.
3. Preventing brain tumour patients from being left to fend for themselves after diagnosis.
4. Increasing research activity in brain tumour biology and medical treatments, which in the long term, will make this disease curable.
5. Educating the wider public about brain tumours, make them understand the disease is not simply a *deus ex machina* in movies and television shows, and instead, can happen to anyone, at any stage of life, of any health level.

How can we achieve this?

- **Peer support** – 1800 number, email list, fact sheets, basic information on treatment options and practitioners, links to other not-for-profit groups.
- **Political lobbying** – participating in enquiries, writing letters
- **Informing the media** – Letters to the editor, press releases, information sessions to attract reporters.
- **Talking about the disease to colleagues, associates, and friends where appropriate** – A brain tumour illness is not a source of shame. Advocating for the needs of brain tumour patients will be easier the more people are made aware of how difficult life with a brain tumour is. Still, there can be problems revealing a diagnosis to employees and colleagues. I personally discuss in great detail the problems faced by a ‘cousin’ of mine, who has a history of this disease and is the motivation for my advocacy.
- **Convincing pharmaceutical companies and scientific institutions to conduct further research treatments for brain tumours.** Brain tumours are considered an ‘orphan disease’, because relatively few people will develop one. BTAA would like weighting placed on the devastation they cause when calculating the metric for research priorities.

The number of advocates is small, and naturally there are differences in opinion on how to advance from this point. BTAA believes respectful debate is preferable to anaemic consensus of a few. We ask that you join BTAA and help lead people from all areas of society into collective action for people with brain tumours and those who will be diagnosed.

Yours sincerely



Matthew D Pitt
Chair

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