

SUBMISSION

FUNDING FOR RESEARCH INTO CANCERS WITH LOW SURVIVAL RATES

-NEOPLASMS-

Dr Sigrid Denehey

Clinical Neuropsychologist and Clinical Psychologist

The Professional...

Since completing an undergraduate unit in Neuroscience at the University of Tasmania, I have been fascinated by the human brain; so much so, that I went on to complete a Doctor of Psychology (Clinical Neuropsychology and Clinical Psychology) at the University of Western Australia. I have been working as a neuropsychologist in the public and private sectors in Tasmania for the past five years.

As you may or may not be aware, neuropsychology is the study of brain-behaviour relationships. Neuropsychologists have been trained in neuroanatomy, neuropsychopathology, theories of cognition, psychology, research design and statistics, and use this knowledge to diagnose and treat the behavioural and cognitive effects of various neurological disorders.

I have assessed a number of patients with, and read extensively about, the various neoplasms (brain tumours) of the human central nervous system. I always found the area fascinating from a neurological perspective, and, as a professional, I found it relatively easy to separate the condition from the person. That was until the 7th of December last year, when my 62 year old father was diagnosed with a Grade 3-4 glioma.

The Personal...

My father, Ashton John Denehey, was a highly intelligent man. His academic and professional accolades were numerous. Dad worked as a barrister and solicitor in litigation, namely motor vehicle accidents and medical negligence, and he was the senior partner of one of Tasmania's oldest and most prestigious firms. He had the highest professional ethics and morals, so much so, that he was named Chairman of the Disciplinary Tribunal in which grievances against other solicitors' professional conduct was heard.

He was also a real community man. He was an incredible footballer and he was immensely proud of the years he played at his local club, the Channel Saints, in Snug, Tasmania. He went on to be President of the club for a number of years and also sat on the Tribunal of the Huon Football Association. His love of his community saw him do a great deal of pro bono legal work over the years.

However, most importantly, dad was an incredible father. He worked tirelessly to make sure that my brother and I were given the best education possible and to lead the best life that we could possibly lead. He was without doubt the pillar of our family. He was so excited that he was due to become a grandfather in April this year; sadly, he will never get to meet his grandchild.

I had been worried for many months that dad may have some form of neurodegenerative condition. His behaviour had changed, he regularly "got the wrong end of the stick" in conversation and he was complaining about deteriorating vision. When I urged him to ask his ophthalmologist whether his

deteriorating vision could be neurological, his doctor discovered that he had a homonymous hemianopia, and he was sent for an MRI the next day.

The MRI revealed a golf ball sized lesion in the right temporal lobe. Given the location, dad's age and sex, I knew that it was highly likely to be a glioma. I hoped and prayed that that would not be the case, because such tumours are exceedingly aggressive and ostensibly impossible to treat. The day after the scan, dad saw the neurosurgeon, and the tumour was resected within the next few days. The surgery went well and dad was recovering nicely, so much so that he was discharged home four days later.

Dad had been home three days when he developed severe headache and nausea. It appeared that he had developed a meningitic process. He was admitted to ICU and given broad spectrum antibiotics; however, no cause of infection was found. In order to keep dad neurologically stable, his blood pressure had to be kept very high (around 230/240), which of course put significant strain on his heart and circulatory system. After nine days in ICU, dad had a catastrophic brainstem stroke and passed away – three weeks after the initial diagnosis. The neurosurgeon said that he had never seen a response like dad's in his entire career. I was six months pregnant at the time, aged 31, and my brother was 23.

In the end, I was able to be grateful for the way in which dad passed. It turned out that he had a glioblastoma (GBM), the most aggressive form of adult brain cancer. In all likelihood, this would have meant that had he not developed cerebral inflammation, we would have watched him rapidly deteriorate over the course of 6-12 months; he would have become significantly cognitively and physically impaired despite the recommended chemotherapy, radiotherapy and countless resections of the tumour as it kept relentlessly growing back.

A neurosurgeon once told me that resecting a GBM was like trying to get all of the raspberry out of a punnet of raspberry ripple ice cream; it is simply impossible. At this point in time, there is absolutely nothing that we can do.

I have always tried to support charities for neurological diseases that I felt were largely underfunded. Up until recently, my favourite was the Motor Neurone Disease Association. So, when it came to dad's funeral, we felt that it would be more beneficial if people were able to donate to a brain cancer foundation in lieu of flowers. I actually had to Google it, because no charities (aside from the Cancer Council) came to mind (and whilst the Cancer Council is a fabulous organisation, they already receive a good deal of funding). Hence I came across the Cure Brain Cancer Foundation, and we were able to raise over \$12,000.00 in dad's memory.

Whilst donating in memoriam makes a fabulous contribution, it is a drop in the ocean of what is required to fund research into this area.

The take home message

I appreciate that trying to find funding in the current economic climate is a significant challenge; however, when considering where funds may be allocated I would strongly urge parliament to consider the following:

- The significant majority (around 90%) of brain tumours diagnosed in people over the age of 50 are highly aggressive gliomas;
- The average life expectancy ranges from 6 – 18 months for GBMs and 2 – 3 years for astrocytomas;

- Patients with these tumours are typically required to undergo chemotherapy, radiotherapy and further tumour resection in order to get the best quality of life;
- Despite having to go through this arduous adjuvant treatment, patients will steadily deteriorate physically and cognitively;
- At this time, being diagnosed with one of these tumours is a death sentence.

What am I asking for?

All that I am asking is that the Federal Government considers allocating some additional funds for further clinical trials in this area in the hope that one day we will be able to better understand:

- a) Why these tumours form; and
- b) How best to treat them (or better yet, stop them from forming in the first place).

If I were not about to have a baby in three weeks I would have filled this submission with the relevant research and statistics; however, I trust that this will be covered by the numerous other submissions that will no doubt be received, and have instead opted for a professional and personal insight into this particularly cruel form of cancer.

I will never be able to fully separate the patient from the disease again. It might be too late for my dad, but I would give anything to prevent other families having to go through what we did.