

Private Submission

Select Committee into Funding for Research into Cancers with Low Survival Rates

Submitted by:
Brendan Spain
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Dear Senator Catryna Bilyk and Fellow Committee Members,

My name is Brendan Spain and I am a long term survivor of a Grade 3 (malignant) brain tumour.

I welcome Senator Bilyk to the exclusive domain of brain tumour survivors. As Senator Bilyk now understands the world of brain tumours (either benign or malignant) is certainly an interesting and frustrating one to live in.

My brief history is as follows:

- With no prior warning signs I collapsed at work from a seizure on 11 August 2004. The next thing I remember is being pushed through the doors of the Royal Melbourne Hospital.
- Diagnosed with a Grade 3 brain tumour (anaplastic astrocytoma) in the left frontal lobe. I was 46 years of age and a senior figure in the banking world.
- First operation on 20 August 2004.
- Initial paralysis down right hand side.
- Prognosis was 18months to 3 years.
- Right hand side now functioning but hand/eye coordination affected.
- Second operation on November 4, 2004 with third operation to remove plates and screws from skull section in late 2013.
- 40 Radiotherapy sessions. No chemotherapy at that time due to non-specific targeting of tumour.
- Epilepsy, fatigue and inability to resume work are many continuing side effects.
- 43 MRIs (next one in August 2017) to date. There were other scans performed during 12.5 years of post brain tumour life.
- Married with two children. My wife was also 46 and my two boys were 12 and 16 years old at the time of diagnosis.
- My neurosurgeon is Professor Andrew Kaye and my Neurologist is Professor Stephen Davis – both are with the Royal Melbourne Hospital and both are Directors of the Royal Melbourne Neuroscience Foundation.

I raised \$25,000 for the Royal Melbourne Neuroscience Foundation and was also a guest speaker at their annual ball in 2015 (along with Carrie Bickmore).

In regard to part a) of your inquiry: ***‘the current National Health and Medical Research Council funding model, which favours funding for types of cancer that attract more non-government funding, and the need to ensure the funding model enables the provision of funding research into brain cancers and other low survival rate cancers;’***

- Brain cancer accounts for just 3 per cent of Australia’s cancer deaths, but it is the leading cause for people under 39. In its malignant form it is almost 100 per cent fatal. About 1600 Australians are diagnosed each year, and about 1200 will pass away. It “disproportionately affects young people and cuts them off in their prime” (a quote by Professor Andrew Kaye in an article published in the Herald Sun Sunday Body and Soul supplement on April 5, 2015).
- In my 12.5 years of being in the brain tumour medical world I can see how the funding models work at the government level. In plain-speak, money is given to “common” (I use this term only to describe the number of people diagnosed) cancer types that exhibit increasing survival rates. Breast and prostate cancer survivors are two such types. And with continuing advances in medical research breakthroughs the survival rates are going to increase still. This is a **wonderful** result. It tends to become a return on investment equation and these cancers clearly provide the return. A fantastic outcome for all concerned.
- With breast cancer women are far more proactive and far more organised than men when it comes to fundraising. Most men are still in the mindset that if they close their eyes then the issues surrounding their particular cancer will disappear.
- With brain tumours, the low survival rates do affect fundraising. When a person dies from brain cancer, often the family and close friends are too exhausted and too grief stricken to continue to raise money.
- In my experience the various institutions that conduct research into these low survival cancers have always been impacted by the lack of government funding. Non government funding falls back onto impacted individuals and their families for fundraising.
- There are in excess of 125 brain tumour types. To fund research into all of these would take an extraordinary amount of funding and an endless number of researchers. The main focus of brain cancer research is on Glioblastoma (GBM – Grade 4). This is the worst brain tumour and the one with very, very low survival rates. Patients diagnosed with GBM live an average of 18 months. Some do not make it past 6 months.
- See attached link as to the WHO reclassification of brain tumours last year: <http://braintumor.org/brain-tumor-information/understanding-brain-tumors/tumor-types/> (Click onto the FAQ’s and go to the bottom of page 5 – FAQ 7) and read the last line to gain an insight into how the WHO is thinking about brain tumours in 2017). This ‘thinking’ has not really changed for a number of years.
- A lot of cancer types have relatively non-invasive detection tests or at least very minimal invasive procedures to verify or not whether a person has cancer. With brain tumours the only definitive test is an MRI or CAT scan. A single once off in life scan does not clear anyone of being detected. It is only a snapshot at that point in their life cycle.

The current cost of an MRI is approaching \$600 (I have lost touch with the cost of a CAT scan). I would argue that the minimum number of MRI's or CAT scans per person over their life cycle would be five. Then it becomes a simple equation of **5 x \$600 (should the cost stay the same) x 25 million which equals \$75 billion dollars.** That equation is very basic to say the least but it does give a tangible funding number to start any discussion about the **detection** of brain tumours; the research funding will be on top of this. This \$75 billion dollar number is unrealistic but it highlights the difficulty of brain tumour detection.

In regard to part b) *'the obstacles to running clinical trials for brain cancers and other cancers with relatively lower rates of incidence, with regard to:*

- i. funding models that could better support much-needed clinical trials, and*
- ii. funding support for campaigns designed to raise awareness of the need for further research, including clinical trials;'*

- In my view any obstacles to running clinical trials will be 'ownership' of the running of these trials. That could be: which hospital, which research facility, which state etc.
- Another obstacle to running clinical trials is sourcing patients who are willing to participate (particularly those with malignant brain tumours).
- Part ii. should really be part i. as campaigns to raise awareness for much needed research should give a greater profile to existing research which in turn (and depending on results) will gather speed and momentum in extracting further government and non government monies. Success in the brain cancer cure will bring its own prestigious rewards to the facility that gets the results.

c) the low survival rate for brain cancers, lack of significant improvement in survival rates, and strategies that could be implemented to improve survival rates and;

- Part c) is all about success in both research and trials; but it should include an early detection model. The list of strategies to improve survival rates at this point in time is very short; almost empty. The main question is why do people get brain tumours. Is it a function of their lifestyle, is it hereditary, is it external forces etc. We could also separate out child and adult brain tumours because seeing a child with any sort of brain tumour is a very depressing sight. In adults it is also depressing but at least (depending on their age) have had a chance of living.
- I have made many changes to my lifestyle by way of diet, exercise, positive outlook etc but it may not be the panacea for the next person. I will say though that personal attitude, great family support, great medical support and the ability to listen to your body are the non-negotiable ingredients that any cancer patient needs to have in order to beat the odds.
- Externally, a lot of things have changed since my diagnosis in 2004. Support groups have been set up and brain cancer nurses have been embraced by a number of hospitals.

- A lot of good reading material is available but it all depends on the individual as to whether she or he wants to participate. A lot of people do not want to know and simply want the cancer cut out. You have to respect their choices and rights. Diagnosis and treatments are very sensitive times for people and not all will want to express their thoughts in this type of forum.

d) other relevant matters.

- This is really a line that “screams out” to say we can provide the funding but we are not sure what else to do.
- Again from where I sit I can say that there is always “hidden” discrimination if a brain cancer wants to return to work either part or full time.
- Brain cancer always has many side effects. The side effects have also not been researched to any great extent. Side effects include: epilepsy, depression, visible physical side effects from the various surgeries or treatments, marriage break-ups, drug addiction, suicidal tendencies, financial troubles etc. There is no template for side effects when it comes to brain operations because too little is known about the brain to predict outcomes. Each person will be different and even then they may not make their problems known. Side effects can be seen straight away or it may take some years to present.
- I can honestly say that I have been fortunate in that even in my darkest hours, days, weeks etc I did not give up hope at all. My family were also there (and still are) to support me and drive me forward. I made a statement early on in my condition to my neurosurgeon that I would be one of his success stories; and so far I am.
- ‘Other relevant matters’ is a list as long as you want it to be. It really needs to be closed down in order for this committee to function and to carry out a successful investigation.
- I do believe that the number of people involved in this committee (which I count to be in the high 40’s) is too many. Half of that number is too many. So I would also include in other relevant matters; that your committee is too large.
- The Committee needs to have personal experience (i.e. Senator Bilyck and a number of other committee members who have had close friends or family members go through this experience) to be advocates for brain tumour affected people both living and deceased.
- I am personally prepared to be a consultant, witness or anything else that you may need or want because there will continue to be collateral damage to those people let down by another Senate Committee that does not achieve an effective outcome.