

Submission to the Select Committee into Funding for Research into Cancers with Low Survival Rates.

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In May 2015, at the age of 38, and three months after the birth of my second child, I was diagnosed with a Grade II Glioma. I was told that I could expect to live another 10-12 years and I underwent an awake craniotomy in July 2015. I should have been enjoying my new baby and time away from work, but instead I was recovering from two brain surgeries, could not walk and was paralyzed with fear and despair about my diagnosis and my shortened life expectancy. It has taken physiotherapy and psychological counseling for me to slowly start coming to terms with what has happened to me and the uncertainty that lies ahead for my young family and I. More than anything, I am concerned for my children not having their mother to love them and support them into adulthood.

Since joining a support group for brain tumours and brain cancers, I have come to learn more about brain cancer at its more advanced stages, the suffering and grief it causes, its terribly low survival rates and the lack of funding into clinical trials and research.

I would like to raise the following points for consideration by the Senate Committee:

- **Better responses by Health Professionals in responding to patient symptoms of brain tumours:** I had experienced loss of sensation and heaviness in my left leg three times over three weeks before I went to my GP for advice. I asked if I needed a brain scan as I was concerned I may have MS. My GP said no and that I needed to see a Physiotherapist. I went to a Physiotherapist who advised I had a lower back nerve irritation. Over a number of days my symptoms worsened and I presented to a different GP who advised me to go to the emergency department. I underwent testing to rule out stroke and it was suggested to me that I could be suffering from anxiety or stress related symptoms. Thankfully, MRIs were ordered for my brain and spine and MS was named up as a possibility. At no point was the possibility of a brain tumour

named as a possibility. I understand that it is not a simple issue to diagnose a brain tumour, however, improved training and awareness of health professionals in the possible symptoms of brain tumours and partial sensory seizures is recommended.

- **Survival Rates:** Brain cancer has a low survival rate and compared to other cancers, there has been lack of significant improvement in survival rates over time. The life expectancy for a diagnosis of a Grade IV Glioma is often 12-15 months with treatment. Across all brain cancers, the five-year survival rate in Australia is only 22% which is low compared to other cancers. Survival rates would improve with increased funding into brain cancer research, improved access to clinical trials and awareness raising campaigns.
- **Funding models into cancers with low survival rates:** The current National Health and Medical Research Council funding model favours funding for types of cancer that attract more non-government funding such as; breast cancer, prostate cancer and leukemia. There is an urgent need to for this model to allow provision into research into brain cancer, rather than favouring the more already well-publicised cancers.

Thank you for taking the time to consider this brief submission. As outlined above, my experience of brain cancer is informed by my own diagnosis and experience of brain cancer. The suffering caused to individuals, families, workplaces and communities due to the low survival rate of those with brain cancer should not be underestimated. I look forward to reading the Committee's recommendations and hope for a better future for the patients and families of those diagnosed with brain cancer.