Monday 6 March 2017

Committee Secretary
Select Committee into Funding for Research into Cancers with Low Survival Rates
Department of the Senate
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Dear Committee Secretary

Funding for Research into Cancers with Low Survival Rates

It is exactly three years today since I took my partner, Ms Leanne Percival, to the Emergency Department of our local hospital, and learnt that she had a brain tumour.

For about a week beforehand, Leanne had had a severe headache, vomited every morning, and been incredibly drowsy. Her GP had given her a medical certificate – actually two, in case she felt that she needed an extra day off work. But when her headache worsened, I felt we couldn't wait to see a different doctor or a specialist, so we went to the hospital to try and find an answer. Leanne was given a CAT scan and the tumour was found. Within a week, she'd had her first resection, and once the wound had healed sufficiently, she began radiotherapy and chemotherapy. Over the next 17 months, Leanne endured 30 ten-minute sessions of radiotherapy; three different chemotherapy regimens; two further resections; surgery to install a shunt; frequent MRIs; a cocktail of steroids and pain-relief medication; regular stays in hospital to treat infections; and finally, intravenous infusions of Avastin.

Leanne was diagnosed with a Grade IV brain cancer, Glioblastoma Multiforme or GBM. Her prognosis was poor: we were told that there was no cure for this cancer and that even with the gold standard treatment of concurrent chemotherapy and radiotherapy, median survival was 12-15 months. We pinned our hopes on Leanne being one of the very few who would make 5 years. She wasn't. Leanne died a little over 17 months after I took her to the Emergency Department that first time.

The impact of her illness and death have been immense. I left work to care for Leanne, and for our young daughter, and have not yet returned to the workforce. During radiotherapy, we travelled 100 km per day for treatment: 3,000 km in six weeks. We subsequently moved from our small rural community to be closer to family and treatment options, and to give Leanne a better quality of life.

We took advantage of the help and information that was available to us as we made decisions about Leanne's treatment. This included the Brain Tumour Association of Australia (BTAA), the International Brain Tumour Alliance (IBTA), the Cancer Council of NSW, brain tumour support groups, and Leanne's oncologists, surgeons, and brain cancer nurse coordinators. We investigated the possibility of clinical trials in Australia and of treatments only available overseas such as immunotherapy and dendritic cell treatment. From memory, most clinical trials at that time were Phase 1 trials, based on safety, not efficacy. By the time it became obvious that none of the treatments we had tried were working, Leanne was no longer eligible to take part in a clinical trial.

Based on my experience as Leanne's carer, I would make the following points for the Committee's consideration.

- Compared to many other cancers, brain cancer has a very poor survival rate. Those who do survive may well have neurocognitive defects caused by their cancer or its treatment. This means there are few survivor-advocates to raise awareness of the condition and the need for funding and research.

- Carers are limited in their capacity to advocate around the disease while the person they are caring for is alive. Once that person is dead, carers may be burnt out by their experience. Again, this means there are few carer-advocates raising awareness of brain cancer or advocating for funding and research, compared with other cancers.

- The impact of funding research on improving the prognosis of people diagnosed with cancer is undisputed. In the past three decades, the 5-year survival rates for people with prostate cancer and breast cancer have improved 35% and 18% respectively. For brain cancer, there has been only a 2% improvement (source: CureBrainCancer.org website).

- Brain cancer is not a common cancer, however it is one of the most expensive to treat. Of all cancers, brain cancer places the heaviest financial burden on households and has the highest per-person lifetime economic cost (source: *The Cost of Cancer NSW – report by Access Economics,* Australia wide, April 2007). In other words, the economic impact of brain cancer is disproportionate to its frequency.

- Brain cancer research is not well funded. Brain cancer receives less than 5% of federal government cancer research funding (source: CureBrainCancer.org website). Government funding of research into brain cancer would hopefully lead to a reduction of the high economic costs of this disease, and therefore seems like a sound investment, regardless of whether this funding is matched by non-Government funding.

- A number of medications are listed on the PBS for use in treating cancer, but are either not available to brain cancer patients, or are only available at great cost. For example, at one time Leanne would have benefitted from the use of Filgrastim (a medication used to treat low blood neutrophils resulting from chemotherapy), however this drug was not available to her, even though we were willing to pay the $2,000 purchase price. To use Avastin, we anticipated a final cost of up to $20,000, although this drug was approved on the PBS for patients with other types of cancer.

- The models used in traditional clinical trials do not seem suitable for rare and aggressive cancers such as GBM. These models rely on having a large sample size, with patients randomly assigned to either the control or the experimental group and testing taking place over a long period. GBM patients do not have the luxury of time. Instead, new adaptive models of research need to be used, such as the proposed GBM AGILE trial system. This system will match treatments with a patient's individual tumour biomarkers, allowing for more effective, personalised medicines. It will enable the testing of experimental new drugs and the repurposing of drugs and methods being used to treat other diseases. And, it will allow new patients and

treatments to be included in the research as insights are gained, saving valuable time. This approach seems to be the only way that we can make progress on treating this insidious disease.

I thank you for the opportunity to prepare this submission, and look forward to hearing the outcomes of your inquiry. It is my genuine hope that this inquiry will lead to a better future for the patients and families of those diagnosed with brain cancer.

Yours faithfully,

Linda Ferguson