

Thank you for taking the time to read of our family's ordeal with brain cancer.

My name is Steven Coote and I am married to Gillian, and have three beautiful children. I am a school Principal, and Gillian is an educator of exceptional talent. She changes the lives of so many young people by speaking potential and hope into their lives. She believes that every young person that she teaches has the capacity to be exceptional. She is a beautiful mother, and a unique soul.

Gillian though, is no different to other sufferers of brain cancer. She is young, she is full of possibility and potential. She is important in the lives of our nation as she prepares our young people for futures that need a deep sense of thought, of creativity. Everyone who has been struck by brain cancer is bubbling with potential, which is why this disease needs to be stopped.

On the 8th of August, 2012 while running on our home treadmill, Gillian suffered an intense migraine – it came from nowhere and as she described it was like her head was struck by a bolt of lightning. The pain was almost crippling. She decided to go to bed, assuming that it was just a headache and perhaps she could sleep it off.

Her headache lasted 2 days – and with each hour her condition became decidedly worse. She became confused, incoherent, her gross motor skills were no consistent with her usual dexterity as a dancer. I knew that there was more going on with Gillian than a simple headache.

I booked her in to see our GP.

After some preliminary test, an emergency CT scan and a report we were told that Gillian, a fit and athletic 37-year-old mother of 2, had a tumour the size of an orange on the front left side of her brain. No one is prepared for such a diagnosis – EVER!

Our world was thrown upside down. No warning signals, no lead in symptoms, just a run, a headache and a steep spiral down to a diagnosis that would change our life forever. As I did my own research on treatments, on surgical possibilities, on survival rates and on different types of brain cancers it became apparent to me that this type of cancer was not a sexy one. It was a cancer that struck at the very nature of who Gill was – it was her brain, her intellect, her emotion, her creativity, her potential. Brain cancer had very little research, ridiculously low levels of research funding and an unchanged prognosis for those in our community that present such amazing levels of potential and possibility, predominantly striking down our children and our young adults.

We were in Perth at the time of Gillian's diagnosis, and treatment responses were slow. With a 10 centimetre brain cancer in her head there was mixed approaches to treatment, different suggestions for surgery and surgical outcomes. As an educator I inquired to the neurosurgeons as to what the research suggested was the best way forward – the response was simply not good enough. I was told there was little research by comparison with other cancers. What was consistent from all of the specialist's we spoke to was the approach to resigning ourselves to a likelihood of early death.

How does such a suggestion happen in the 21st century? As we learn of increasing levels of intelligence and intelligence systems, we have a disease that kills our most promising at an alarming rate, and yet there seems little we can do about it. I remember thinking that we had given in to this bastard and we were willing to do so without a fight.

My request to the Senate Inquiry is that you look at the lives that are cut short, the lives that are stolen from our children, from their parents, from our young mums, from our fathers. It is not right, particularly when the possibility exists for us to explore the possibilities for a cure. Where is the person standing up for our children and saying "I will fight this battle for you" or "my life's work will be about ensuring the necessary funding is made available to fight this nasty, ugly insipid disease."

The cure is on us as a nation – my request of the Senate Inquiry is to act in the interest of those being struck down by this bastard!

Steven Coote