

10th March 2015

Committee Secretary
Senate Legal and Constitutional Affairs Committee
PO Box 6100
Parliament House Canberra ACT 2600

Re: The Regulator of Medicinal Cannabis Bill 2014

Dear Committee Delegates,

I have a personal interest in the regulation of Medicinal Cannabis for a number of reasons. My 43 year old sister recently passed away from a recurrent brain cancer, an insidious and debilitating disease which robbed her of many things in her struggle, and unfortunately she lost her courageous battle. She suffered for almost three years with terrible symptoms, including loss of mobility, loss of cognitive function, loss of some reasoning, intractable headaches and very early on in her diagnosis, terrible seizures and seizure activity.

Firstly I wanted to say how distressing and disturbing it is to watch someone you love suffer so much from a terrible diagnosis and to witness their decline is heartbreaking. It was a dreadful time for our family, made more emotional as my sister has left behind a three year old daughter. My sister's seizures were a particularly nasty symptom that she had to endure on a daily basis, sometimes multiple times daily. These were also of course witnessed by her young daughter. I find it heartbreaking to think how they coped.

After enduring all surgical and chemotherapy options, my sister was told she was entering a palliative phase of her disease, words none of us can get our heads around, especially at such a young age. For people such as my sister, the psychological and emotion implications of such terrible news are also insurmountable. Anxiety and depression play a big part in the palliative patient's psyche.

The ongoing seizures and seizure activity continued and her brain tumour steadily got worse. It was the seizures that caused my sister much distress and despite many trials of conventional anti-seizure medication, nothing worked. These seizures could occur at any time and any place, they often caused her to fall and injure herself and of course, sometimes she was caring for her young daughter at the time. What was particularly distressing was when they happened in public and she even lost friends as a result of such episodes as they could not cope with witnessing such events.

She saw many doctors, including a world-renowned epilepsy expert. The number of anti-seizure medications rose and with that the associated side effects. She was hospitalised a number of times in the Royal Melbourne Hospital in an attempt to trace the seizures on EEG and titrate medications. Nothing worked. Eventually she was flown home to Tasmania in an Air Ambulance and admitted to a Palliative Care Unit in Hobart to be near her family and friends. The doctor in Hobart prescribed Clonazepam, a strong anti-seizure medication which unfortunately led to increased sedation and further decreased mobility.

My parents, both aged around seventy years of age, found this whole journey very difficult. My sister started to research the use of medicinal cannabis in order to control the seizures. She had been an industrial relations lawyer prior to her illness and did struggle with the legal implications of considering a product that is illegal in Australia. It was around this time that it became more difficult to source medicinal cannabis as it was prevalent in the media and a number of people had been reported to the police for both manufacturing and administering the drug.

After fruitless research we were offered biscuits made with cannabis, my sister advised to consume three per day. We were told the level of THC was low, due to the extraction process used by the maker. We will never know the exact THC levels and cannabinoid that were in these biscuits. What we do know is that they very quickly reduced her seizure activity to a point where they stopped completely. These most distressing events were now finally controlled by these biscuits.

As we were unable to purchase medicinal cannabis, due to legality and misinformation, my parents were forced to purchase these biscuits and my sister struggled with the legality of this.

If medicinal cannabis is legislated for medical use it would save people like my family struggling with the issues in sourcing cannabis. My dear sister finally had some peace from these terrible events. This increased her confidence and quality of life (which there is very little of for the majority of palliative patients).

I am a Registered Nurse and have worked in acute care in the public system for over 20 years, many of these in Oncology. I can state without any doubt that in my clinical experience, medicine and science do not have all the answers. I have seen countless patients with intractable pain, nausea and vomiting and seizures and not just in the oncology setting. As a nurse it is distressing not to be able to help alleviate symptoms of the patients in your care and watching my sister suffer was excruciating.

Despite concentrated efforts of medicine, a large number of patients have to live with debilitating symptoms of terrible disease processes. Anecdotal evidence, of which there are countless examples, shows there is enough proof that medicinal cannabis would help thousands of people to experience a better quality of life. Please enable this by introducing the relevant legislation to allow it.

There will of course be countless interested stakeholders in this debate, but I strongly believe the primary issue should be one of humanity. Anything we can do as a society to help our most vulnerable people, palliative patients, people living with debilitating disease, chronic illnesses, not to mention children suffering from many forms of paediatric problems is the right thing to do.

Lastly, there are very few moments of joy and light in the journey of a terminally ill person, particularly when they are young, but we found some semblance of relief when my dear sister's terrible seizures were resolved. Please consider such people when making your decision regarding this Bill. It is paramount and time critical for many of our fellow suffering Australians.