

13th March, 2014

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

Dear Committee,

I started smoking cannabis regularly when I was about 16. I had an extremely difficult childhood and cannabis helped me cope with the aftermath. At no time have I ever felt that cannabis was doing me harm. In fact, as I approach 50 years of age, I have no health conditions at all. I have never been a big consumer of alcohol. As recently as two years ago I also went without cannabis for a period of twelve months, without any issues. I certainly don't have to have it, but I prefer to.

I have worked for the majority of my adult life and I do not believe that being a regular cannabis user has impacted me professionally in anyway. Rather, in a professional capacity, I have been the recipient of several awards; [redacted] Local Government Association) Local Government Merit Award for distinguished service to the community through the Local Government [redacted]; EMRC (Eastern Metropolitan Regional Council) Certificate of Appreciation in recognition of significant contribution and dedicated service as a Councillor; and the Zonta International Woman of Achievement Award for establishing ASCA (Adults Surviving Child Abuse) [redacted].

I have one child named [redacted] who is [redacted] years of age. [redacted] has been sick for about seven years now. She has two rare blood disorders, PNH (Paroxysmal nocturnal hemoglobinuria) and MDS (Myelodysplastic syndrome). There is no cure for either condition. A bone marrow transplant may cure the MDS but one in four that have this procedure die, so we keep this option as a last resort. [redacted] is expected to develop AML (Acute myeloid leukaemia) and with her underlying conditions her chance of survival should this happen is poor at only 10%. [redacted] is technically pre-leukemic and her conditions are considered life threatening.

[redacted] currently receives treatment at the [redacted] Centre every fortnight. The treatment she receives is Soliris (Eculizumab) which costs the Federal Government about \$500,000 a year. That is just the cost of the medicine. [redacted] was approved for treatment by the Life Saving Drug Committee. Soliris is referred to as pre-chemo and helps stop the PNH from causing damage to her major organs. There is no time limit on the treatment [redacted] receives. She has been receiving Soliris for at least two years now and will continue indefinitely.

As you might imagine our lives are currently very difficult. [redacted] is on a Disability Payment and I am her Carer. We have next to no local support and our family is mostly in [redacted]. The medical professionals involved in [redacted] case have literally offered us no hope and that is an awful situation to be in, for what is there if there is no hope? As any parent would, I started looking into alternative treatments, because I simply refuse to accept that my only child will continue to get sicker until she dies.

What I found when I went looking for alternative treatments was medicinal cannabis. I spent months doing research online and discovered enough evidence to support [redacted] giving it a go. I was confident from my own cannabis use that it was certainly not going to harm my daughter. Initially I did my best to ensure that she had a small amount of cannabis to smoke daily which I knew would improve her appetite, reduce her stress and help her sleep, which it did.

It took me some months to find a local source of medicinal cannabis that I could trust. Fortunately for us, cost was not an issue as the medicine was offered freely. This is not uncommon in the cannabis community, that those with the ability to make medicine, do so freely and simply to help others in need. I think that is a very special and beautiful thing and is a world away from the business of big pharmaceuticals.

We initially tried a high THC strain, 'Blueberry Lush' to be exact, and made a cannabis infused coconut oil. [redacted] has a blood test done fortnightly when she has her conventional treatment so we have always been able to monitor her results quite closely. Two weeks after she began medicinal cannabis we saw some remarkable results. Her platelet count was within the normal range, where it had not been since she first became sick six and a half years earlier. To be honest, this was enough assurance for me that we had made the right decision in trying medicinal cannabis.

I monitor four of [redacted] blood lines specifically, haemoglobin, white cell count, platelets and neutrophils and all of these responded well to medicinal cannabis. Unfortunately, only a few weeks after commencing medicinal cannabis [redacted] travelled to Perth to visit a sick relative and could not take her medicine with her. We have also obviously had supply issues, so her results since starting treatment have been up and down. When she has access to medicinal cannabis her blood results slowly improve and when she does not, they slowly drop. We try our best to maintain supply but it is not easy. [redacted] has also not required a blood transfusion since she started medicinal cannabis in July 2014 whereas she was previously receiving a transfusion every three months. It took a little while to establish the correct dose and [redacted] has had no negative reactions. [redacted] is a public health patient.

We have no intentions of stopping the use of medicinal cannabis. We believe wholeheartedly that cannabis is capable of curing [redacted], and this is what we strive for. We implement a large number of other measures to improve [redacted] health, as much as our limited means allow. This includes breaking the law daily by the use of hemp seeds and hemp oil, a super food. If it were possible I would take [redacted] overseas to better facilitate

medicinal cannabis treatment as Australia is woefully behind many other countries in embracing cannabis as a medicine.

I completely support the Regulator of Medicinal Cannabis Bill, in so much as it provides a clear way forward in this country, but I sincerely believe that there is no legitimate reason for cannabis to be illegal in the first instance. Through the extensive research I have undertaken I am convinced that everything the government has ever told us about cannabis is a lie. In fact, I am outraged at the current status of cannabis, as any intelligent person would be. This outrage is only intensified when I contemplate the status of hemp, hemp seeds and hemp oil in Australia. It is beyond ridiculous and certainly beyond rational.

In terms of access to medicinal cannabis I favour the dispensary model as demonstrated in some states in America. Medicinal cannabis should be readily available to patients and carers and needs to be affordable. As a carer I would specifically like to be able to grow enough cannabis plants for her to be able to juice the raw plant and use the raw plant in cooking. Raw cannabis is non psychoactive and has demonstrated excellent healing properties. I do not know for sure but suspect maybe a dozen plants might be required to allow for daily juicing. I believe being able to grow our own cannabis is a very important element in moving forward. If we have to pay for medicinal cannabis our access could be as limited as it is now.

I cannot adequately relay my frustration and disillusionment at being in a position where, as a desperate and terrified mother, I am and have been pleading with government to access such a healing plant that we have been forbidden from using, in order to try and save my daughters life. I have never felt so separate to government. Please be aware that many Australian families are not waiting for permission to use medicinal cannabis, and if the Regulator of Medicinal Cannabis Bill is unsuccessful what it means is that families like mine continue to deal with the black market. That is as simple as it gets; we, the patients and carers, either move forward with government, or we continue as we have been in dealing with the black market. I believe a compassionate government would help its people, particularly those that are seriously ill or dying, and that is what I ask that you do.