

Regulator of Medicinal Cannabis Bill 2014

Submission

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

12th March 2015

Re: The Regulator of Medicinal Cannabis Bill 2014

Dear Committee Delegates

**A Quality of Life decision
In the interest of patients, their families
And the future of Australian Health Care**

I have carefully considered my options for submission and have come to the conclusion that you will receive many formal, medically based submissions. So I feel, as I am writing as an advocate for my seriously ill child, and I believe also a voice for other families and patients who do not have a voice; then a submission reflecting the 'real' use of Cannabis as a medication and its benefits to a patient, and my heartfelt dialogue, which is based on a medical background, will be more representative of the message I wish to convey.

I will speak specifically in relation to the use of Cannabis as a medication to treat intractable epilepsy in children, however I wish to make it known that the underlying message relates to all seriously ill patients across Australia.

According to the UN Convention on the Rights of the Child *"Sometimes, we have to think about the rights in terms of what is the best for children in a situation, and what is critical to life and protection from harm"*

The UN Convention on the Rights of a Child is a long and complex document, however a number of articles within the document (here-in modified specifically from the child friendly version) relate to children suffering from severe and currently untreatable conditions, and to their parents who have devoted their lives to saving their children, including:

Article 2:

All children have these rights, no matter whether they have a disability, whether they are rich or poor. No child should be treated unfairly on any basis

Article 3:

All adults should do what is best for you. When adults make decisions, they should think about how their decisions will affect children

Article 4:

The government has a responsibility to make sure your rights are protected. They MUST help your family to protect your rights and create an environment where you can grow and reach your potential; and to this end, shall take all appropriate legislative, administrative and other measures to the maximum extent of their available resources and, where needed, within the

framework of international cooperation

Article 5:

Your family has the responsibility to ensure that your rights are protected

Article 6:

You have the right to be alive. Governments shall ensure to the maximum extent possible the survival and development of the child

Article 23:

You have the right to special care if you have a disability, as well as all the rights in this Convention, so that you can live a full life. Governments will recognize the rights of the disabled child to special care and shall encourage and ensure extension of assistance for which application is made and which is appropriate to the child's condition; including in relation to health care services - and including the exchange of medical, treatment (and other) information relevant to the needs of children with disabilities and to the governments own education, improving their own capabilities and skills in these areas

Article 24:

You have the right to the highest attainable standard of health care for the treatment of illness and rehabilitation of health, safe water to drink, nutritious food, a clean and safe environment, and information to help you stay well

Governments shall take appropriate measures to:

- 1. Diminish infant and child mortality rates***
- 2. Ensure the provision of necessary medical assistance and health care to all children***
- 3. Combat disease and malnutrition***
- 4. Abolish traditional practices prejudicial to the health of children***

Article 27:

You have the right to food, clothing, a safe place to live and to have your basic needs met. You should not be disadvantaged so that you can't do many of the things other kids can do. Governments shall take appropriate measures to assist parents to implement these rights

According to the UN Convention on the Rights of the Child - My Alice has the right to be alive and the right to the best health care for her individual needs - to stay well, to live a full life and, so she can grow and reach her potential ... her family and her government have a responsibility to ensure these rights are met ... and it is my belief that we should be working together to ensure the best possible outcome for my Alice; and indeed for all Australians.

My Alice has the right to use a medication, which helps to keep her alive and well; and as I have spent the past 9 years researching and dedicating my life to ensuring Alice's health and wellbeing, coming to the conclusion that Cannabis has a place within our Medical Care Plan, then it should be recognized also by those who have the capacity to make decisions regarding the legalization of Cannabis as a medicine, that Cannabis has a place within Alice's Medical Care Plan, within the Medical Care Plan of other Australians and, a place in the future of Australian Health Care.

My daughter Alice started on a trial of Cannabis as a medication to control her seizures in February 2014. In July of that year I became publically involved in the Medicinal Cannabis debate.

Alice has a rare genetic condition called CDKL5, with no known cause or cure; a condition marked primarily by the severity of its uncontrollable seizures, and by significant intellectual and physical disability.

By the time Alice was 25 weeks of age she was having up to 30 seizures a day (often up to an hour long), and I was told she was going blind and dying; *"It's like your baby's brain is exploding, she cannot survive, I don't know how she's survived this long"*

So, as many mothers in my situation have decided before me: I vowed I would devote my life to ensuring, to the best of my ability, that Alice would survive and would have the best possible life I could give her.

From early on I found doctors and specialists who would support me to treat Alice Bio-medically, and although Alice improved, and her seizures even at times seemed controlled, there was always something missing; a light in her eyes perhaps (?), and the seizures would return with relentless vigour after short periods seizure free.

By February of last year it was again agreed that Alice would not survive and our little family remained in the 'survival mode' pattern that so many families with seriously ill children are familiar with; life revolving around caring, eating, sleeping (if you are lucky enough) and working, when you can, to pay the bills and keep a roof over your head.

Then I watched a program on Tara O'Connell and Mullaways Cannabis Oil. Although I was previously aware of the supposed benefits of Cannabis as an anticonvulsant, I had been reluctant to trial this option. However a friend, who also comes from a medical background, encouraged me to do so. We did our research, we discussed a trial with Alice's medical specialist ...and Alice is now not on any other anticonvulsant medication.

I am not going to tell you that we have complete seizure control – because we don't ... but what we do have is a little girl who has made significant progress physically and intellectually and who now has less frequent, shorter and less intense seizures, from which she recovers so much better than before. However, Alice's medical condition is particularly complex and her seizure type particularly severe (as with so many children whose parents are desperately looking for a way to save our children) so sleep, stress, pain, temperature and any number of other factors can affect seizure activity even with the best treatments available. We live everyday with the fear of SUDEP (Sudden Unexpected Death in Epilepsy), and that is a reality many of us face. Therefore, I do not advocate for Cannabis as a medication alone, but Cannabis as part of an overall medical treatment plan, overseen by doctors or experts who understand the complexities of serious health conditions.

I have from the very beginning said I believe in research and a medical model for dispensing (or at least a model overseen by experts in the area). I don't believe it is important to waste time researching whether Cannabis works or not. We know it does. I think learning from, and/or being involved in the research that is already being undertaken around the world would be invaluable; I believe that what is important, is to research how best to treat individual patients or specific medical conditions with Cannabis.

There is much misinformation available, and hype, about the use of Cannabis, but the truth is ... Cannabis is not a Magic Bean Stalk; you can't just throw any old Cannabis seeds out into your garden and expect a magic plant to grow that will heal all your health needs and magically solve all your problems ... you wouldn't walk into a chemist, grab any old box of medication off the shelf and take it home to say *"Here, take one of these 3 times a day and your seizures will stop"* ... no medication (pharmaceutical or non pharmaceutical) has that magical property.

So I believe research into various Cultivars (in other words, various ratios of CBD:THC and other Terpenes and chemicals) is vitally important so that, as in countries like Israel and America, we have a range of cultivars available specific to individual patients' medical needs.

According to reports from some families and specialists, patients in America, for example, are treated with a range of Cannabis products relevant to their needs and specific to eg. Seizure management, pain, nausea, sleep etc.

Main stream medicine does not have all the answers, and many currently available pharmacological medications are not the best option for so many seriously ill Australians (and many have side effects worse than the conditions we are treating) However, I do not believe that one medication alone will cure all ills or prevent all illnesses. There is a need for Cannabis users to be able to access the services and expertise of our medical system and many pharmaceutical medications are important as adjunct or supplementary medications useful in treating both acute and chronic conditions, in conjunction with Cannabis treatments; as well as Cannabis being used as a stand-alone treatment for some conditions. I do believe thought that as patients, or advocates for patients, we should be able to make CHOICES in relation to our own health care, and Cannabis as a medication is a choice we should all be able to make.

Legalisation, research and medical regulation will help us to sort out these and many other critical issues, which will ultimately lead to better health outcomes for all Australians. Surely that is what is most important here – Individual stories might highlight the need for change ... but making changes which benefit all people in need of medical support (long term this will be each and every one of us!) should be our primary focus as an outcome.

Medical support (or professional expertise) will also help take out the guess work, and the trial and error problems so many of us face; it will mean that if we turn up to hospital, our Cannabis treatment wont be denied, and our medical professionals will be better educated and more able to assist us in providing the best treatment options for patients. I have a mutually respectful relationship with Alice's specialist (and all her other doctors), who not only supports our use of Cannabis, but will listen to my research, answer my questions, discuss my opinions in relation to my daughters care ... and work together with me for the benefit of the only one in the room who really matters – Alice. Not every Australian is in this position; and even with our current level of support, I still crave the medical support of a knowledgeable, holistic team. A team who is not concerned regarding their own professional credibility, or future, if legal action was to be taken.

So from first speaking out publically till now I have advocated for Cannabis to be legalised, researched and medically dispensed for the benefit of individual patient needs and relevant to specific medical conditions: No one should be denied quality treatment, especially when mainstream treatments have failed to treat or manage their health conditions.

During this time I have also been actively supporting rescheduling high CBD medications. Currently CBD medications are classed as a Schedule 9 drug, meaning they have no medical value, and are illegal; if CBD is rescheduled to S4, it can be prescribed by doctors, and administered by families and carers without fear. I believe this is a good step in the right direction as far as rescheduling higher THC medications also, and it would be evidence of a growing level of understanding by our governments and medical profession ... it also would provide the opportunity to observe on a large scale, how beneficial Cannabis can be.

I have also been supporting legalisation of Hemp Seed as a nutritious food source. Hemp Seed is already sold in our health food shops and should be legalised for human consumption. Many of our children (and others) progress so well on Cannabis treatments because of the nutritional benefits of this wonderful plant.

I set up a "*Medical Cannabis Kids*" Face Book page with the aim of sharing information with families, medical professionals, politicians or anyone else who wanted to learn more about Cannabis (with a focus on children and epilepsy but much more than that alone). I understand this is an emotive topic, so I have tried to distance myself from biased opinion and self promoting, and try to keep this page focussed on: positive success stories, media which highlights the issues, and research or other articles which provide unbiased information to those who seek it.

At the very least, Medical Cannabis needs to be legalized for research purposes so that its benefits to children like my Alice can be medically ascertained to the full extent; so that it can then be medically

monitored and medically dispensed. My wish is to see Cannabis made available, like any other drug, where doctors are able to prescribe it to patients who would benefit from its use.

In the best interest of moving forward towards a future where Cannabis becomes a mainstream treatment of acute and chronic health conditions within a framework of Australian Medicine, I believe we need to legislate in consideration of:

- A register of users (and carers) – Ensuring protection from prosecution and authorization for use, and as a format for compiling data
- Patient support – Providing patients with appropriate health care support from doctors who are educated, or through specialist services available to ensure patients have access to support in relation to their therapy with Cannabis as part of their overall Health Care Plan. No families should be forced to make health care decisions for their children without the assistance of medical expertise
- Round table discussion – where the opinion of health professionals, policy makers and patients/carers are put forward in such a manner that common sense leads to practical best outcomes being achieved in relation to the medicinal use of Cannabis in Australia
- Meta Analysis of existing research and information from around the world, and within Australia, be carried out – to ensure knowledge is collated in relation to the use of Cannabis; without wasting the time or money required to replicate research
- Review of overseas models of legalization and dispensing – in order to ensure past mistakes are not repeated and the future of Cannabis use in Australia is recognized as a benchmark or model of excellence
- Policies put in place to ensure consistency of quality and supply that meets patient specific demand – currently most patients face variable quality and shortage of supply issues
- Consideration for the economic benefits of Cannabis as a financial crop, to be used in rotation with Poppies or other agricultural endeavors, supporting farmers across Australia
- Other options for growing, use, import and export based on; patient specific need, medically beneficial varieties and economic growth potential determinants

Research, legalization and medical dispensing, under a patient specific framework, of Cannabis as a medication is important for the health, safety and protection of seriously ill and disabled people across Australia. Choice of medication to ensure best health care options – is a Human Right. Australians deserve a medical grade, medically regulated, medically dispensed product that is recommended and dispensed specifically for their individual health requirements and as part of their overall Health Care Plan.

In this submission I have no intention of reiterating the facts presented in research papers otherwise available to you; however I would like to report 3 facts that are relevant specifically to my Alice, and to children like her:

5. At least 30% of people with epilepsy do not have seizure control on currently available pharmacological anticonvulsant medications
6. Epilepsy is the most common chronic brain disorder; 3 times more prevalent than Multiple Sclerosis, Parkinson's Disease or Cerebral Palsy - affecting more than 5,000 Tasmanians alone
7. Epilepsy ranks in the top 5 causes of avoidable death in the 5-29 year age group; with SUDEP, Sudden Unexpected Death in Epilepsy, the most likely cause of death

Cannabis has been proven, in research and on a case-by-case basis, to help control seizures and improve/manage symptoms associated with acute and chronic health conditions.

Legalisation leading to best possible health care outcomes for children like my Alice, who is at risk of SUDEP, and for all Australians suffering acute and chronic health conditions can be achieved: for both now and into the future.

Cannabis as a medication plays a role in the future of Australian Health Care – now is the time to work together to ensure best health care outcomes for all Australian's who deserve the right to choose Cannabis as their health care option.

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March 2015

