

Sherrí Hickey

Submission to Senate Legal and Constitutional Affairs Legislation Committee

Regulator of Medicinal Cannabis Bill 2014

The bill: establishes a Regulator of Medicinal Cannabis to be responsible for formulating rules and monitoring compliance with those rules for licensing the production, manufacture, supply, use, experimental use and import and export of medicinal cannabis; and provides for a national system to regulate the cultivation, production and use of medicinal cannabis products, and related activities such as research.

Response

The introduction of the 'Regulator of Medicinal Cannabis Bill' to Parliament brings us great hope and we are most grateful to those who have the fortitude and compassion to support this much needed bill. Medicinal Cannabis offers hope to many thousands of people who suffer terrible pain and medical afflictions that affect their daily life.

To live without pain is a basic human right and people have a right to access effective pain management without discrimination according to the Declaration of Montreal 2010.

The declaration states that all people:

Have a right to access appropriate medicines, including but not limited to opioids...

Have a right to ...pain relief treatment that is compassionate, empathetic and well-informed.

Have a right to access best-practice, non-medication methods of pain management...

Have a right to be recognised as having a disease entity, requiring access to management akin to other chronic diseases.

<http://www.iasp-pain.org/DeclarationofMontreal?navItemNumber=582>

Medicinal cannabis offers a much needed alternative pain relief treatment for patients who cannot tolerate the treatments already available, particularly those who cannot tolerate opioids for severe pain. Medicinal cannabis cannot come fast enough for those in pain.

Our submission raises some points of concern that need to be addressed.

Summary of Main Points

- 1. HOW will "Authorised Patients" be selected?**
- 2. WHO decides whether a patient should be authorised?**
- 3. Will the eligibility criteria for medicinal cannabis be too limiting or restrictive?**
- 4. Will criteria include only well recognised and more common symptoms of diseases, as it may yet prove to be beneficial in many diseases and on many symptoms yet unknown?**
- 5. Will the criteria include patients with very painful conditions?**
- 6. Will the GP be able to prescribe medicinal cannabis?**
- 7. A wide variety of product forms and administration routes must be made available.**
- 8. The whole plant should be including in the definition (leaves, seeds, buds, stems, roots).**
- 9. Choice of product and administration must remain with the patient.**
- 10. Time limitations and temporary measures should be put in place.**
- 11. National exemptions from Narcotics Laws needed for patients and carers possessing small amounts of cannabis for proven medical reasons.**

Background

I have two daughters, Emily (15) and Elyshia (19), who suffer from a very painful, rare, genetic condition called Ehlers-Danlos Syndrome and I am the co-ordinator of the Cairns Ehlers-Danlos Support Group that currently has about 15 members. I am also a member of Rare Voices Australia.

Ehlers-Danlos Syndrome (EDS) results from a defect in the way collagen is produced and used within the body. Collagen is a basic building block of the human body and therefore faulty collagen affects every part of the body, most notably the connective tissues such as ligaments, tendons, muscles, skin, venous system and nervous system. This results in varied and wide-spread symptoms that cause severe pain, notably dislocations, subluxations and complex regional pain syndrome. The condition also causes depression and anxiety. The condition can be life-threatening depending on the type of EDS a patient suffers from. The condition also causes problems with the immune system and the way the body processes drugs and medications. As a result many EDS patients cannot tolerate most pain relieving drugs, including opioids, and are left with no real solution to pain. Many young people with EDS have committed suicide because they were unable to face a life of pain and disability.

My eldest daughter, Elyshia, suffers the worst from EDS. She is in constant pain and suffers painful dislocations and subluxations every day of her life. I have seen my daughter screaming in pain on the hospital floor, at wits end, because all options for pain relief had been exhausted and there was nothing left to try.

In November 2014, Elyshia presented a speech, on behalf of Rare Voices Australia, at the launch of Parliamentary Friends of Rare Disease in Canberra, explaining what it is like for a young person living with a rare disease in Australia.

Pain relief is the worst problem for her, apart from not being able to find doctors and specialists who know anything about this rare disease, and not being able to get a quick diagnosis.

Elyshia has drug reactions to almost every type of pain relief she has tried, including all the opiates and anti-seizure medications. The only thing that works for her currently is a 4 day infusion of Ketamine, which means 4 days in hospital every few months when she suffers from Complex Regional Pain Syndrome, which results from a build-up of daily chronic pain.

Elyshia desperately needs a pain-relieving medication that she can take at home to avoid hospital stays.

However, in the United States, many EDS patients are now using medicinal cannabis to control their pain, promote restful sleep and treat depression, and it has allowed them to lead a better quality life.

Elyshia is waiting desperately for medicinal cannabis with higher amounts of CBD and lower amounts of THC to become available, knowing that it will provide her with relief from pain and help to prevent Complex Regional Pain Syndrome from developing.

We are very relieved and grateful to see the Medicinal Cannabis bill is progressing, but would like to raise some concerns that need addressing.

HOW will "Authorised Patients" be selected and WHO decides whether a patient should be authorised?

1. We are concerned that the eligibility criteria for medicinal cannabis may be too limiting or restrictive. Already we see criteria set in place in NSW for cannabis trials only on patients with a terminal illness or severe epilepsy.

We have already experienced such difficulties with CentreLink with their eligibility criteria for the Disability Pension. CentreLink's list of eligible diseases does not cover most of the known 6000 rare diseases and much additional paper work, time and expense was required for us to prove Elyshia's eligibility for the Disability Pension. Most questions on the form did not cover the many and varied symptoms experienced by people who suffer a rare disease, for example dysautonomia (a fault in the autonomic nervous system).

2. We ask that you please do not limit the criteria to include only well recognised and more common symptoms of diseases. Some of the symptoms suffered by patients with rare diseases have only recently been recognised and described, because the diseases are so poorly understood. Some symptoms of rare diseases are yet to be even recognised and documented properly.

3. We ask that the eligibility criteria for the use of medicinal cannabis must include patients with painful conditions such as chronic pain, recurring acute pain, complex regional pain syndrome, fibromyalgia etc.

4. Given that the full extent of the medicinal benefits of cannabis are yet unknown, it would be detrimental to make its use too restricted, as it may yet prove to be beneficial in many diseases and on many symptoms yet unknown.

5. Who will decide whether a patient should be Authorised and who can prescribe it?

We have come across many, many doctors and Specialists who did not have any knowledge or understanding of Ehlers-Danlos Syndrome and the pain they suffer, and were therefore not in a position to make such a decision. We have spent a fortune on doctor shopping trying to find someone who had the knowledge to treat my daughters effectively. Our hope is that other patients don't have to do the same in order to find a doctor who can help them with trialling medicinal cannabis. Often it is the GP who knows their patient best and can make a decision if a trial would be suitable. In regional areas specialists tend to come and go and do not stay long. In regional areas we sometimes have to wait months to see a specialist, such as the pain specialist.

A wide variety of product forms and administration routes is required.

It is from experience that we know that some forms and routes of pain relieving medications are tolerated better than others due to differing genetic profiles, metabolic rates and ages of patients.

For example, Elyshia cannot tolerate any opioids that are given orally, yet she is able to just tolerate IV morphine. This has something to do with the etiology of the disease and how the gastrointestinal tract is affected by faulty collagen, although this is very poorly understood by even the experts on EDS. She is also an ultra-rapid metaboliser of some medications.

For this reason it is essential that a wide variety of different forms of the cannabis product are available, and different routes of administration are available, to suit the requirements of different patients and how they process drugs differently.

Therefore, everything from fresh plant to highly synthetic forms needs to be available.

Different strains of the plant have varying levels of CBD and THC, so different plants may suit different patients depending on their symptoms. Some may need to use suppositories if their condition so determines. Some may prefer vapourising if swallowing is a problem. Recently I have heard of the roots being of medicinal use.

Advice of medical practitioners and pharmacologists is vitally important of course, but the choice must remain with the patient, based on their experiences with their particular condition.

Every part of the plant should be included in the definition of cannabis. We are yet to discover all the usable chemicals in the plant and should not exclude any part of the plant. There are a large number of different chemical elements and combinations to be found in the cannabis plant. It is possible that only natural combinations will have the beneficial results required. It may be impossible to isolate the many chemical combinations that provide relief. So patients must have access to the whole plant, when necessary.

Time Limitations

Whilst the process of changing Legislation is an important one, and we need to get it right, it can also be a very lengthy process. People suffering debilitating and painful medical conditions can't wait. It is inhumane to let them suffer and violates basic human rights.

NSW is starting medicinal cannabis trials but have severe restrictions on who can participate in trials. NSW has allowed exemption from Narcotics Laws for patients and carers using cannabis for medicinal reasons. But what about the rest of us? Those in other states can't wait that long for pain relief and can't move interstate.

We ask that time limitations be placed on this process to ensure efficient and expeditious changes?

We also request that temporary exemptions from Narcotics Laws could be put in place nationally for patients and carers possessing small amounts of cannabis for proven medical reasons while this legal process (which could take years) proceeds?

In summary, medicinal cannabis is a welcome and very necessary alternative medication for people suffering EDS and other rare conditions, particularly those who cannot tolerate opioid based medications. If the above concerns can be addressed, medicinal cannabis can bring about better quality of life for many in our community.

Thank you for taking the time to consider our submission.