

Submission into the Regulator of Medicinal Cannabis Bill 2014

Name: Mrs Lucy Haslam

Dear Committee Secretary,

I wish to make this submission as a parent and carer of a medicinal cannabis user (recently deceased), as an ex Registered Nurse,(25 years' experience) as the wife of an ex- NSW Police Drug squad officer (35 years' experience) and as a concerned Australian citizen. I have extensive knowledge of the Medicinal Cannabis black market in Australia and of many Australian citizens who are being forced into criminality to access adequate pain and symptom relief by using medicinal cannabis.

Whilst my experience is comprehensive and involved I shall endeavour to keep this submission brief and based on my personal experiences.

Up until recently my husband Lou and I had three adult sons. We lost our youngest son Daniel only weeks ago to bowel cancer. He was 20 when diagnosed with stage 4 bowel cancer and only 25 when he passed away on 24th February 2015. He suffered enormously and I will take a long time to recover from the trauma of seeing someone who was so loved and cherished, fighting so desperately to maintain health and indeed life.

The majority of Australians including politicians have little personal experience with Medicinal Cannabis, or indeed any cannabis, as was my case up until as recently as late 2013. Consequently members of the Parliamentary Committee may have the perception that the proponents of medicinal cannabis are largely unemployed, unmotivated, underachievers who contribute less to productive society than most. This was certainly my past perception of cannabis users in general. My opinion was based solely on misinformation and propaganda which had been an insidious part of my conservative catholic upbringing in the 1970s and 1980s. I have since become educated and have a more informed and accordingly more accurate attitude.

My current opinion is vastly different, having watched my son endure a lot of unnecessary suffering, having seen his life improve with medicinal cannabis and now having been in contact with hundreds and possibly thousands of other Australian's who like Dan, turned to cannabis when first line pharmaceutical treatments failed to provide adequate symptom control. I have also come to know many of the compassionate medicinal cannabis suppliers who risk their own freedom to supply the sick with the medicine that relieves them best. This sounds like a romantic exaggeration but it is not. It is the truth!

Dan's experience was life changing for our entire family. He had spent three years on very strong and rigorous chemotherapy. A cruel regime which saw him develop "anticipatory nausea" where just the thought of chemotherapy caused him to vomit violently. My own research leads me to believe that this is not an uncommon occurrence, especially amongst young patients who are undergoing chemotherapy. As Dan's chemotherapy was particularly aggressive and long-term, the symptoms of

nausea and vomiting became so severe he required frequent trips to the emergency department for rehydration and medication. When we could no longer manage Daniel in this way we organised routine hospitalisation every cycle just to try and get him through it as best we could. This was time he spent lying alone in a darkened hospital room away from his young wife. He was so ill he was unable to speak; unable to eat or drink, IV fluids being his only sustenance....just trying to get through the two days till his chemotherapy pump was removed. He would then go home feeling very weak and fatigued and trying to retrieve an appetite to regain the weight which he had just lost, in order to be strong enough for the next round of chemotherapy in a fortnight. As you can imagine, the impact of this cancer treatment was horrendous. There were many periods when Dan and our family was collectively paralysed by depression caused by this vicious cycle. Our entire family's work and life revolved around having someone with Dan during treatment and then helping him to get ready physically and psychologically for the next round. Throughout this time he was also undergoing several major surgeries including bowel resections, a liver resection and peritoneal resection. It was imperative that he maintain a degree of fitness just to be able to survive the surgical interventions he required. It was a very difficult task to do so.

Then one day in late 2013, three years into his treatment, a friend of Dan's (who is a well-respected local Tamworth businessman,) suggested to him that he should try cannabis to tackle his nausea and vomiting. He himself had been introduced to cannabis by his partner as he had endured the rigors of chemotherapy for treatment of bowel cancer two years earlier. He had cannabis left over which he offered to Daniel. Dan's initial response was to say no because he respected my husband and I. We had raised our sons to believe that recreational drug use was wrong and consequently Dan was sure we would not approve.

Then his friend called me to argue the point. Rather than arguing, I was all for it at that stage I felt so desperate. I spoke to my husband immediately and he, like me agreed that this was an option worth trying. Nothing to date had worked with good effect. Dan had tried Maxolon, Stemetil, Ondansetron, Emend, Aloxi and Phenergan as well as benzodiazepines. We could fully comprehend the mounting psychological battle of continuing chemotherapy. Dan's cancer was at that stage not responding to the chemotherapy drugs and the only option was to try the chemotherapy agents which he had originally been unable to tolerate due to the crippling side effects. We knew things were only going to become harder.

Dan's response to the next round of chemotherapy was a revelation. His father rolled him a joint and taught him to inhale. After a couple of drags on a cannabis cigarette, Dan was smiling instead of heaving. He got his colour back and asked for something to eat and drink. We all looked at each other in joyous disbelief, stunned, excited and we all cried with relief. Our son had just used cannabis for the first time and we were happy about it.

For me, the impact of that day has been enormous. Like any parent concerned about their child I now felt an urgency to research cannabis. I used the internet, I read books, I spoke to pharmacists, and I contacted people like Dr Alex Wodak and Professor Lester Grinspoon from the USA. Interestingly, Professor Grinspoon, an Emeritus Professor of Psychiatry from Harvard University, described his own personal experience with his son also called Daniel who like our Dan had succumbed to anticipatory nausea when receiving chemotherapy for cancer. His story so paralleled my experience I could barely

believe it. Professor Grinspoon's son had such a positive response to using cannabis to alleviate his nausea that the Professor went on to make Medicinal Cannabis a major part of his life's work. He is now aged in his 80s!

I read everything I could find including the NSW General Purpose Standing Committee No. 4 report into the use of cannabis for medical purposes. I met with Senators Trevor Khan and Sarah Mitchell who were on that committee and I was reassured by the positivity of the findings of the committee. They were extremely disappointed and frustrated that the recommendations of the committee had been dismissed. I told them I wanted to challenge the NSW Health Minister Jillian Skinner and they wished me well but did warn me that they thought it was probably a futile exercise.

I had a great degree of difficulty reconciling the fact that NSW had conducted an extensive enquiry into the use of Medicinal Cannabis, that the committee had made unanimous recommendations which if adopted would have seen medicinal cannabis use by someone like Daniel, acceptable in NSW and yet, for all the positive outcomes that were possible from that enquiry, The NSW Health Minister had rejected it outright. I spent a lot of time dwelling on this untenable fact.

My disillusionment with a political process which sees a Minister ignore the advice of the Government's own expert working group was intense. We had always been law abiding, community spirited taxpayers and now Dan, Lou and I were criminals in the eyes of the law because we sought relief for Dan. The stakes were high and as a family we decided to take a public stand. I did not feel like I should be considered a criminal. I was just a mother who wanted to ease the suffering of my son. Dan didn't feel like a criminal, he just wanted to stop vomiting so he could have his treatment without losing his quality of life completely. My husband didn't feel like a criminal. He had spent his career locking people up for illicit drug use but this was no different to accessing medicine from the chemist. It was not for ill-gotten gains, it was not for Dan to get "high", it was not to destroy lives or to make black money. It was just to stop Dan vomiting. Nothing more, nothing less!

Dan's Story went public just under one year ago and since then, it has insidiously transformed into an Australia wide campaign for medicinal cannabis to be recognised, legitimised and legalised. During the course of the campaign I lobbied all levels of government. As a family we appeared on current affairs programs on channels 7, 9 and 10, Al Jazeera, ABC, SBS and others. I have been contacted by media from around the country and from outside Australia. I have successfully lobbied NSW Police, NSW Nurses and Midwives Association, the Catholic Church, The CWA, The Cancer Council and the list goes on.

The purpose of this information is to highlight that the interest has been enormous. The support has been enormous and the outcome has been enormous. This is significant for many reasons but for me personally, I now feel a profound responsibility to continue on as a medicinal cannabis advocate in spite of Dan having now lost his battle. Dan was a beautiful, law abiding man who suffered much more than he should have. I wish he had accessed medicinal cannabis much sooner after his diagnosis. Perhaps the outcome would have been better for him. In the very least he would have had less time being violently ill, far less time in hospital, he may have tolerated the stronger chemotherapy when they first tried it, he may have stayed strong for longer. Who knows? He may have even had the cancer fighting response he was hoping for and which other cancer patients have described over recent years.

Pharmaceutical preparations were not enough to manage his nausea and vomiting. When he finally had the benefit of medicinal cannabis he then suffered emotionally because he was made to feel like criminal in this country which he loved. It seems clear to me, that Dan's Story resonated with so many Australians because he spoke with out for himself but also obviously for thousands of other Australians who are sadly in a similar predicament and too afraid to expose themselves. Dan's legacy was one of truth and of justice. The current Australian laws deny the scientific truth about Medicinal Cannabis and the consequence is a system which treats the sick as criminals for trying to manage symptoms such as pain, epilepsy, nausea and the list just goes on and on.

Dan found great relief from cannabis especially when we purchased him a vaporiser. As a non-smoker, he disliked smoking immensely. He was able to continue his chemotherapy without fear and dread each cycle. He was able to spend more time at home with his wife. He was able to maintain his weight instead of the constant yoyo cycle he had endured for three years. Dan used to say there should be a vaporiser on the side table of every chemotherapy chair in the country! Cannabis oil had other benefits which are rarely mentioned elsewhere. His hair thickened up, his skin cleared up and the cavernous mouth ulcers which had been a huge problem for years were now a thing of the past. His gut was more comfortable and his bowel habits were more regular whilst he was using cannabis oil. Dan was able to sleep better and to use less frequent pain relief. These small but important aspects alone should be reason enough to make this available as legitimate medicine in Australia.

Towards the later months of his illness Dan found cannabis oil lessened his need for opiates when the cancer was in his bones. Dan would try to avoid opiate use because of the often significant side effects such as chronic constipation (a serious problem for patients who have undergone substantial bowel surgery as Dan had) He also disliked the drowsiness and memory problems associated with opiates.

Pain relief is a legitimate use of medicinal cannabis which Australia has largely ignored due to the misconception that pharmaceutical preparations are much safer and more medically acceptable. I would argue that they are far less safe, more acceptable only within the current inappropriate legal framework and more poorly tolerated by patients than cannabinoids. Opiates are an increasing source of illicit drug use and addiction, regularly abused in the wrong hands and over prescribed without a second thought by many doctors. This is another great hypocrisy within the medicinal cannabis debate..... studies from overseas countries where medicinal cannabis programs have been implemented, have seen overall reductions in accidental deaths from opiates. (*See attachments titled Medical Cannabis Laws and Opioid Analgesic Overdose Mortality in the United States, 1999-2010 and The Legalization of Medical Marijuana and Incidence of Opioid Mortality Marie J. Hayes, PhD; Mark S. Brown, MD*)

Even the opium poppy fields so prevalent in Tasmania pose a high risk to those who dare to trespass and consume the poppies from the open fields. There have been three deaths in recent years directly attributed to ingestion of poppy plants from the open fields. I have seen these low security farms first hand and I shake my head in disbelief when opponents describe the overwhelming security risks of producing commercial medicinal cannabis in Australia. This is used as yet another reason to deny Australian patients a safe medication. Cannabis simply cannot result in a fatal outcome, no matter how much is ingested. The double standard applied here is not only frustrating but dishonest. At the end of

the day, a patient who receives good effect from opiates can be prescribed opiates; a patient who receives better relief from cannabinoids should be likewise prescribed cannabis!

Another important aspect of commercial production of medicinal cannabis in Australia is the enormous potential for the Australian economy to benefit. Australia's diverse climatic conditions would support the cultivation of broad ranging strains of cannabis which in turn give rise to the large scale capacity to develop the industry from a medicinal aspect (different strains for different medical uses) and from a potential export perspective. There is already considerable interest from overseas markets. For example, when the private company Auscann was granted a license to grow and export cannabis by the Norfolk Island Government last year, they immediately received a huge order from Canada who have a shortage within their own market. Of course this never came to fruition because the Federal Government stepped in and overturned the Norfolk Island Government's decision. This decision stifled a potential new industry for the Island which has languished in economic hardship for many years and a golden opportunity went begging!

Coupled with any lucrative industry is the potential to generate income through taxes. This is surely more salient than the current situation where the black market runs the industry, where taxes are non-existent, where crime flourishes and where patients are at the mercy of unscrupulous dealers who are only in the business for profit. Patients are also vulnerable because they have no consistency of supply, no way of knowing the cannabinoid profile they are taking, they alone are responsible for titrating dosage and so the inherent list of problems goes on.

The Australian Government should be reassured that we have the expertise within our own country to initiate and cultivate a successful medicinal cannabis industry modelled on the best programs from around the world. This debate should be firmly focused on the many positive opportunities and outcomes which would come from introducing medicinal cannabis within a structured and regulated framework.

Australian politicians can no longer ignore the growing call for medicinal cannabis legalisation and emerging facts as they stand in 2015. Some that appear very obvious to me include:

- **The enormous need and public support from within Australia** which is substantiated by the large number of medicinal cannabis users who are compelled to use the product despite it being illegal. I have thousands of emails from such people who contact me on a daily basis seeking help and advice. Our petition on change.org has over 200,000 signatures. Channel 7 conducted an online poll on the night that Dan's Story aired on the Sunday Night program. In 4 hours over 2.82 million Australians voted with the result a staggering 97% in favour of Medicinal Cannabis being legalised in Australia. Other recent polls, both informal and formal have mirrored this result. If widespread civil disobedience is any indication, the government is failing miserably in supporting sick Australians.
- **The prejudices and obstacles being fabricated by the pharmaceutical industry via the medical sector is a hugely significant problem.** When Health Ministers consult with doctors who have no informed interest and no current education about medicinal cannabis (and that would seem to be the vast majority of the medical profession) the most common

outcome is the denial of scientific evidence from around the world, and doctors who cite lack of clinical trials as a reason why there should be no consideration given to the merits of medicinal cannabis. Organisations such as The AMA and The College of Physicians should be required to substantiate their publically stated negative opinions when they are influencing policy decisions of the Government. There has been a recent history of medical representatives making sweeping statements denigrating medicinal cannabis, disparaging anecdotal evidence of people such as Daniel and yet they personally have limited knowledge of the latest research. Facts often quoted are those which belong on the realm of historical propaganda designed to harm the cannabis industry of years gone by. This is all well documented especially in the area of cannabis history originating from within the United States of America.

- **The incessant use of Schizophrenia and other psychological harms of cannabis are continually exaggerated and serve to further misinform public policy and encourage fear.** The use of cannabis (medical and recreational) is enormous, yet the statistics for schizophrenia do not correlate with this growing consumption. I am by no means an expert but recent evidence further dispels this correlation and whilst there are harms associated with cannabis use they must be part of an individual risk vs benefits analysis as indeed all medications should be. A recent study from Germany even indicates that cannabis can in fact be useful in the treatment of schizophrenia. *(See attachment titled Cannabidiol enhances anandamide signalling and alleviates psychotic symptoms of schizophrenia .F M Leweke^{1,2}, D Piomelli^{3,4}, F Pablich^{1,3}, D Muhl^{2,3}, C W Gerth², C Hoyer^{1,2}, J Klosterkötter², M Hellmich⁵ and D Koethe^{1,2})*
- I have been entrenched in this debate for 12 months and I am firmly convinced **that the vested interests of the pharmaceutical companies are impacting significantly and resulting directly in the negative progress of medicinal cannabis in Australia.** Medicinal cannabis is a natural botanical plant which cannot be patented by pharmaceutical companies. Many Doctors seem unhealthily swayed toward Pharmaceutical cannabis derivatives which are less effective, limited in supply and overly expensive. This is one aspect of the clinical trials in NSW which I have brought to the NSW Government's attention and which I could elaborate on if required to do so. I certainly intend to discuss this situation with NSW Premier Mike Baird in the near future.
- **The complexities of managing a botanical plant via the Therapeutic Goods Administration (TGA) are used as an excuse not to progress with the natural plant.** Like putting a square peg in a round hole, it can't be done. But a Cannabis Regulatory Body can work in conjunction with the TGA, not as an alternative but as an adjunct used to administer and regulate medicinal cannabis in order to obtain positive outcomes for legitimate medical users and to protect the wider community from abuse.
- **At the very least cannabis needs to rescheduled.** It is entirely inappropriate that it is scheduled alongside heroin and is also considered a poison. This defies all logic and common sense.
- **The immediate needs of the sick need to be addressed. Clinical trials are welcome but they are time consuming, expensive and not the panacea for all scenarios. If an**

individual with a significant medical need is using or wants to use medicinal cannabis, they should be supported by their GP, Specialist, pharmacist, community and government to do so.

I have now personally met numerous folk regularly using medicinal cannabis for **cancer pain**, for **chronic pain**, for **Parkinson's like symptoms**, for **Alzheimer's disease**, for spasms resulting from **spinal injury** and **brain injury**. They report positive outcomes. They are happy and encouraged by their results! Why are they afraid to share their success with their GPs and specialists?

I have met children with **Dravet syndrome** and **CDKL5** whose parents were told the best they can hope for is for the child to be maintained on a regime of dangerous pharmaceutical drugs that can cause weight gain, blindness, blood abnormalities and fatality amongst others. When this plethora of prescribed drugs fails to control seizures, these desperate parents try Medicinal Cannabis and they witness a transformation of their child. Many children go from being severely brain damage to relearning lost skills, to gaining new skills, to re-joining their peers at school, becoming more mobile, developing language, literacy and numeracy, forming relationships, and best of all, achieving seizure control or complete seizure eradication. When some brave parents have dared to come out publically to describe their children's experiences, the AMA and senior Paediatric Neurologists have demeaned their success as anecdotal and even called it merely a result of the placebo effect.

The Australian Government is failing these very sick children and their families. They are criminals who risk a knock on the door from Police and children's services yet their children are far healthier due to the illegal administration of cannabis than they were with the vast amounts of legal pharmaceuticals which have the very real potential to kill them. Doctors should be supporting them and learning from them. These families should not have to worry about where they can get the medicine from, what is in it? How much should they give?, what happens if it is seized? How can they pay for it? What happens if the child is hospitalised? What happens if their supplier is caught and their supply is confiscated? Some of these families are even being assisted to have their own private "grows" established in secret locations as a means of maintaining a regular, consistent supply. Can you imagine the stress and desperation attached to this scenario which is being played out all around Australia?..... And no, I am not exaggerating!

We should be ashamed that we are adding to the enormous burden of having a very sick child. We should be supporting parents who are only driven by love for their children and their desire to achieve the best health outcome for them, whatever the risk!

I recently met a woman in her 60's who had endured **MS** for years. Medication had not worked. She was preparing to commit suicide as she lives alone and was so immobile the only way she could get up her front stairs was to crawl up on her bottom. She had refused the offer of medicinal cannabis tincture on two previous occasions because it was illegal. On the third occasion she reluctantly agreed to try, knowing that she had nothing to lose.....now instead of planning her suicide she is planning to return to work! Her recliner chair and walking frame are now unused reminders of the immobility and pain that almost caused her to take her

own life. She has her life back, is fully mobile and pain free. The AMA would describe this result as anecdotal or merely placebo effect. She describes it as miraculous! We should be happy for her but she remains a criminal because she takes cannabis tincture to maintain her newfound mobility.

I am also concerned for returned veterans with **PTSD** who are being let down by a Government which has placed them in harm's way and now make them criminals as some try to deal with the negative psychological impacts of being on the front line. The Department of Veteran's Affairs owes it to these men and women to examine medicinal cannabis as a valid treatment for PTSD as other countries like Israel do.

These are just a few of the hundreds of examples I have come in contact with, usually as a result of individuals seeking help, advice and information. I feel a duty to make this submission on behalf of the many good Australians who are living in fear of being criminally charged when they have valid medical reasons for using cannabis.

Last year I used cannabis oil myself as a topical application for a skin cancer on my face. I had the cancer biopsied and it was confirmed as a solid micronodular basal cell carcinoma (BCC) which the doctor intended to excise. It would have resulted in a large scar on my right temple along my hairline and extending in toward my eye. Dan suggested I try some cannabis oil on the area whilst I waited to have the surgery performed. After six weeks of a second daily application of cannabis oil, the area festered up, looked very angry and then just disappeared. The literature I had read described this process exactly, yet I was still surprised because the result was so incredible. In November last year I asked the doctor to re-examine me. He couldn't find any trace of the cancer yet he remarked firmly that "it will come back"! I conveyed my experience to Mara Gordon from the USA. Mara is a cannabis alchemist who came to Australia for the Inaugural Australian Medicinal Cannabis Symposium in November last year. When I told Mara about the skin cancer and in particular about the doctor's comments she confirmed to me that it was a very effective treatment for skin cancer and that I could be reassured that the skin cancer was unlikely to return. She explained that cannabis applied topically was a skin cancer treatment that was growing widely in the USA and she commented to me and I quote; "why on earth would a country such as Australia, with the highest incidence of skin cancer in the world, not be embracing cannabis oil for topical treatment of skin cancer?"..... Why indeed?

- **I believe it is critical that Australia adopts a unified approach to Medicinal Cannabis.** It would be a very unacceptable situation if citizens were detrimentally affected based on their state of residence. It is bad enough that Australians currently travel overseas to access the medicine they require. If some states adopt medicinal cannabis programs and others don't, people will be forced to move interstate and there are many adverse consequences of this possible scenario.
- **I also believe that it is imperative that if a medicinal cannabis scheme is implemented, the legal quantities that are permitted must be sufficient to meet the needs of the patient.** The current Terminal Illness Cannabis Scheme in NSW, whilst a welcome

introduction, the amount of cannabis permitted is insufficient and unrealistic to many patients' individual needs, especially because of the current lack of adequate supply. Patients still need to deal direct with a black market that is inconsistent at best.

- **Any Medicinal Cannabis Scheme should likewise include children with epilepsy and other terminal conditions such as cancer.** As outlined already, there are a significant number of minors for whom pharmaceutical preparations have failed. Most of the children with uncontrolled seizure disorders can respond well to CBD only preparations and hence the THC scaremongering is not at all applicable. There are some children, who in my view would benefit from treatment with cannabis which contains at least some THC, such as young cancer sufferers with pain issues. Again it should be an educated medical and parental decision based on risk versus benefit analysis for the individual child. If the main concern is fear that the child will get “high” then many other prescription drugs currently being administered to children should also be considered inappropriate. Again the hypocrisy of this scenario is bewildering!

In conclusion, I would like to briefly touch on the work of Helen Kapalos. Helen is an experienced journalist who worked with Chanel 7's Sunday Night Program. She was the presenter for Dan's story. She gave her time and help freely when I organised the Medicinal Cannabis Symposium late last year. She has been so compelled by what she has learnt as a journalist about medicinal cannabis that she has left secure employment to pursue the Australian Medicinal Cannabis Story and to document it on film. This film is currently in the edit stage and Helen has personally funded most of this project. I have been privileged to be working alongside her in this quest and have been privy to many of the transcripts from interviews she has conducted in Israel and within Australia.

The information she has gleaned particularly from many world renowned specialists in Israel has cemented my personal view that medicinal cannabis is an emerging science which is already yielding great benefits to millions of patients from around the globe. The 20,000 plus participants in the Israel program is testament to the fact that this form of treatment can be successfully implemented in Australia and can be tightly controlled without any negative impacts on the broader community.

Australian patients have a basic human right to access medicinal cannabis particularly when first line treatments have failed them. Lack of knowledge on this important subject from within Australia is an abject failure of the medical profession who have not kept up. It is not a valid reason to ignore the science. The Australian Government has the opportunity and the responsibility to make amends to all the “Daniels” out there who stand to have their suffering alleviated.

It is time that leadership, common sense and compassion be enacted by the Australian Government and be reflected in updated Australian laws that adequately meet the needs of the Australian people.

I thank you sincerely for the opportunity to share my experience and opinion.