United in Compassion Ltd

13 December 2020

Dear Sir/Madam,

RE: Submission to WA Select Committee into cannabis and hemp. For the purpose of this submission my focus will be on medicinal cannabis.

I am writing to you as Co-Founding Director of United in Compassion Ltd (UIC), a registered Charity focused on supporting access to medicinal cannabis for all Australian patients who could benefit from it.

Background of United in Compassion Ltd.

UIC was formed in 2014 by myself, Lucy Haslam a former registered nurse from NSW and my son Daniel Haslam, a 24-year-old stage 4 bowel cancer sufferer. UIC has a Board of 6 and a Scientific Advisory Board including Scientific Researchers and Health Care Professionals.

Together with my husband, Lou Haslam (a former NSW Police officer with 35 years' service and much of that spent in the NSW Drug Squad and heading the Drug Unit for the Northwest of NSW), my son and I began to lobby the NSW Government and then Premier Mike Baird in 2014, to change the law to enable access to medicinal cannabis for patients like Dan who had debilitating symptoms which were unrelieved by conventional medications and therapies.

At that time, Dan was four years into a five-year battle with terminal cancer. His quality of life was very poor. He was suffering with unrelentless nausea and vomiting, anorexia, pain, insomnia, and depression. As parents, we were staunchly opposed to recreational cannabis use, and we had little comprehension of the therapeutic value or use; however we were so distressed in witnessing his suffering that despite our negative views of cannabis, we encouraged Dan to try it.

From the moment Dan tried cannabis we could not ignore the benefits it immediately gave him and in his final year of life, he enjoyed a quality of life that he had lost due to the progression of his disease and the treatments he required. I embarked on a mission to research why cannabis had proved to be such effective medicine for Dan? It seemed wrong to have to criminalise ourselves in order to relieve Dan's suffering. This was just 12 months after the 2013 NSW Senate inquiry into Medicinal Cannabis, which had unanimously recommended that cannabis be reintroduced for patients like Daniel. Despite this strong support, the then NSW Health Minister Jillian Skinner had completely dismissed the findings of the inquiry, opting instead to do nothing and to leave cannabis as an illicit substance which remained listed on the poisons register.

Fortunately, Premier Mike Baird met with Dan, recognised that things needed to change to demonstrate genuine compassion for the sick and he became a strong advocate for change in NSW.

From NSW, I moved the focus of lobbying to Canberra and following my address in the Parliament, a Cross Party Committee headed up by Richard Di Natale the then head of the Greens, was formalised and The 2014 Regulator of Medicinal Cannabis Bill was developed. The Committee had representatives including every major party and many independent MPs. It was a demonstration of co-operation and compassion that was rarely seen in Canberra. By late 2015 it was at the point whereby a groundswell of public support urged the Bill on, and it looked like being successful in its passage through the levels of Parliament.

On the 24th of February 2016, (the first anniversary of Dan's death) the Federal Government took things in an entirely different direction and instead changed the law by amending the Narcotic Drugs Act.

It was not until after this occurred that I realised that the switch by the Government from supporting the cross-party Regulator of Medicinal Cannabis Bill to amending the Narcotic Drugs Act was politically motivated and a high-level demonstration that cannabis bias was alive and well within the Australian Government. At the time of the Legislation passing, there was no written regulation whatsoever to underpin it …. it was a clear demonstration of policy on the run.

The rejected Regulator of Medicinal Cannabis Bill had recognised that cannabis was not like regular medications due to the complex molecular structure, abundant strains and chemovars and naturally occurring variations; and that regulating cannabis via the Therapeutic Goods Administration (TGA) would be problematic. By Amending the Narcotic Drugs Act, the Government diverted the conversation away from compassion and access. It put cannabis medicines firmly in the camp of unapproved compounds and the outcome has been reflected in the years of patient access issues from that time until the present.

UIC considers that the actions of the Government indicate determined efforts to use regulation to control and limit access at every step. Medicinal Cannabis was fast tracked into a regulatory limbo. Broadly speaking it became 'Approved yet unapproved', and the pathways for prescribing were complex and involved approvals at both State (and Territory) and Federal levels.

<u>The Cost Barrier.</u> The most pressing issue at the present time is cost to the patient because of the regulatory system adopted.

Most medicinal cannabis products are unapproved for use in Australia due to limited data on the safety and efficacy of these products. To date, only two medicinal cannabis products have been approved in Australia by the Therapeutic Goods Administration (TGA) (i.e. **registered** in the Australian Register of Therapeutic Goods). These are Sativex® (for the treatment of multiple sclerosis) and Epidyolex® (for the treatment of certain epileptic conditions). However, neither of these products are listed on the Pharmaceutical Benefits Scheme (PBS), meaning they are not subsidised by the Government.

To meet the genuine clinical needs of patients with eligible conditions, the TGA provides the following pathways under the Therapeutic Goods Act whereby patients can legally access unapproved medicinal cannabis products:

- The Special Access Scheme (SAS), or
- The Authorised Prescriber Scheme (APS), and
- Clinical Trial Schemes (CTX and CTN)

To be eligible for reimbursement in Australia, medicines must be subsidised under the Pharmaceutical Benefits Scheme (PBS). Only registered products are eligible for reimbursement, although not **all** registered products are reimbursed. Unapproved products are not eligible for reimbursement. If a product is not listed on the PBS, then the patient must pay the full cost.

Neither of the two approved medicinal cannabis products, Sativex® and Epidyolex®, are reimbursed under the Pharmaceutical Benefits Scheme.

Of the three TGA access pathways listed above, only medicinal cannabis supplied under a clinical trial is (generally) free of charge. Products supplied under SAS or APS are **not** free of charge, although it is open to the company's discretion whether it provides the product free of charge or at a subsidised cost.

The cost of accessing medicinal cannabis can be substantial, particularly in patients who use medicinal cannabis for long-term treatment, and the cost of treatment can therefore quickly become unaffordable for patients and their families. UIC is regularly contacted by patients struggling with the financial costs and for specific conditions like Paediatric Epilepsy, these costs are unreasonable and outside the capacity of most Australian families.

As an example, a Brisbane family recently sought help as they were paying $1700 per month for a product via an Authorised Prescriber for their nine-year-old with intractable epilepsy. The child had previously been prescribed Epidyolex but could not tolerate the adverse side effects of severe diarrhoea. The hospital treating neurologist refused to provide any other cannabis product and the family returned to the illicit market for supply but eventually became too fearful of the criminal risks involved and so they sought an external Authorised Prescriber. Additional to the huge product costs incurred there were the substantial costs of accessing the doctor. It is not unusual for some doctors to charge hundreds of dollars to do the initial application, then additional fees to repeat and even take phone calls in relation to the patient. Eventually UIC negotiated with a cannabis company to provide heavily discounted product, but this is the exception and not the rule. This family is not alone in their situation and there is no Government help on offer. The dilemma places not only enormous financial burden but also adds huge stress to an already disadvantaged family.

The regulation of the supply chain of cannabis medicines is also a contributor to cost. Whether suppliers grow or import from overseas the controls placed on every step, the excessive waiting periods for approvals due to an under resourced Office of Drug Control (ODC), the net effect is high product cost. Other availability issues also come into play due to the layers of control, and it is not uncommon for patients to receive out of stock notices, which required them to swap to another product or endure no access at all.

The TGA has made some recent changes to address supply issues and now some products will be able to be substituted as products are moved into categories with other like products. Time will tell if this is successful but there are many who believe that another set of problems will emerge because of these changes.

Discriminatory policy

Another group adversely affected by high costs and discriminatory policy are Veterans with Post Traumatic Stress Disorder PTSD). The Department of Veteran Affairs (DVA) is the body governed with approving and providing access to medicinal cannabis treatment for Veterans and has adopted a patchy, inconsistent and uncompassionate approval process to medicines in this category. This situation has also been brought to our attention by doctors who have tried on successive occasions to prescribe cannabis for their patients after comprehensive consultation, presentation of

supporting research and including the successful treatment of the Veteran on medicinal cannabis either obtained via a registered and approved supplier or from an illicit source. Frustratingly, the DVA will approve medicinal cannabis for pain whilst continuing to refuse it for mental health conditions, including PTSD.

This has left many veterans financially and socially vulnerable, often on other medications with a range of complicating, and sometimes serious, side-effects including medications which cause suicidal ideation. DVA's policy is compounding mental health burden for these Veterans when they are refused access to cannabis which many are already using successfully albeit illicitly. There is no doubt to us that the policy increases the risk of suicide for such Veterans, and this is clearly unacceptable. UIC has made submission to the Royal Commission into Veteran Suicides on this matter.

Driving discrimination

Driving laws throughout Australia are generally discriminatory towards genuine medicinal cannabis patients including those with legal prescription. Lacking a scientific basis, Australian driving laws do not revolve around impairment but rather the mere presence of Delta Nine Tetrahydrocannabinol (THC). In some states, a randomised drug test that depicts the trace of THC in the saliva is enough to result in an automatic loss of licence and criminal charges whether the driver is impaired or not. This same standard is not applied to any other legally prescribed medication. Many Australian patients have lost their access to employment and the many freedoms/ rights enjoyed by having a licence. This impacts most heavily on those who live in rural and remote communities where a licence is essential to life. It should not be a choice whether a patient relieves debilitating symptoms or retains their driver licence.

Workplace attitudes and drug policy

It is becoming clear that some workplaces do not have the right information about cannabis medicines and impairment. Only recently we were contacted by a law firm representing a client who had been dismissed by his employer for using CBD which is un-impairing, and which had been legally prescribed. We have heard of a Police officer relegated to desk duties and his weapon removed due to his honesty about being legally prescribed cannabis. I am sure that situations are not isolated and others like these will continue to increase as more patients are prescribed cannabis. There seems to be general confusion about the legal status and about impairment issues related to medicinal cannabis use with many still confusing recreational usage with medical usage.

Attitudes of Health Care Professionals

Another ongoing barrier involves the frequently less than positive attitudes of Health Care Professionals. Whilst the number of prescribers is improving, there is still hesitancy, suspicion, and reluctance by many to include medicinal cannabis prescribing in their day-to-day practice. UIC believes that this is due to several factors including personal bias, unfamiliarity with the Special Access Scheme and Authorised Prescriber route and unwillingness to make the required time commitment to each application, lack of education and confidence to prescribe, fear of being held legally responsible for negative outcomes due to the unapproved status of the medicines and negative messaging from peek medical practitioner organisations. It is not unusual for patients to report being shown the door when they raise the issue of cannabis as a potential treatment with their GP or treating specialist.

This negative attitude also frequently permeates hospitals, respite centres and aged care facilities and is reflected in staff ignorance about the legal status of the medicine, and the rights of the

patient to access their legally prescribed medicine within the setting. Sometimes family members are required to attend twice daily to administer the medicine or worse still, the medicine is withheld altogether.

To try and address this problem, UIC has worked successfully with State and Territory Nursing bodies including the national body, the Australian Nursing and Midwifery Federation (ANMF) to try and overcome ignorance and improve acceptance by nurses in the workplace. In 2019 all Nursing Bodies mentioned, formerly endorsed medicinal cannabis as a treatment option for Australian patients. It is hoped that this positive shift will provide some improvements for patients across various settings.

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In 2019 UIC was integral to the push to gain a Senate Inquiry into the Barriers to Patient Access to Medicinal Cannabis. The issues raised above were all part of that inquiry and whilst UIC was reasonably pleased with the recommendations of that inquiry in 2020, most of these recommendations have been largely ignored by the current Federal Coalition Government including the recommendation to return to an Independent Regulator if access issues were not resolved.

<u>The main barriers to access in summary</u>

Cost including the inability for cannabis medicines to be subsidised in the existing system. This results in remaining reliance on the black market and exposure of genuine patients to many risks from prosecution and exposure to potentially contaminated and inferior products. UIC believes that despite the rapidly increasing rate of medicinal cannabis prescriptions via SASB and AP route, the vast majority of Australian patients remain reliant on supply from illicit sources.

Discriminatory Driving laws which are unscientific in approach and which in some states result in automatic loss of licence for the mere presence of THC is a huge barrier to more patients taking advantage of cannabis medicines and the high safety profile they offer.

Lack of education of the health care workforce results in ongoing stigma and bias and patients are commonly turned away from doctors unwilling to even consider prescribing cannabis. The Government has done little to improve the education of the health care sector or the general public and instead, advertising restrictions placed on prescribers and the supply chain, have the combined effect of diluting the confidence of the workforce and stifling knowledge about the potential of cannabis medicines.

Ongoing stigma permeates the general public and most remain confused about the legal status and how or where to go to find accurate information.

In closing, UIC believes that there are few risks associated with permitting industrial hemp for human consumption if quality is maintained. Currently quality discrepancies have already arisen between imported and locally produced cannabis products and the Australian growers have fought to have the same quality standards applied to imported products without success.

Yours sincerely,

Lucy Haslam
Co- Founder Director
United in Compassion Ltd

Any members of the Committee are invited to attend the United in Compassion 2022 Australian Medicinal Cannabis Symposium (May 20-22) which will focus on all aspects of medicinal cannabis including ongoing barriers. Please advise me via email if you would like to attend as UIC's guest.

2022 Symposium – UIC (unitedincompassion.com.au)