



mcua

Medical Cannabis Users Association of Australia

1st November, 2019

Medical Cannabis Rip Offs result in patients charged with self supply.

On Friday in the Supreme Court of Appeal in Brisbane the appeal by Mr Alex Dimitropoulos against his conviction in the district court for the cultivation of cannabis for medical purposes was adjourned. Unfortunately he is one of many patients being dragged through the judiciary for this using cannabis “unlawfully”.

It is estimated that close to a million patients are now seeking access to cannabis medicine. The govt figures show around 20,000 patients now have approvals for access to legal products. Many patients, like Mr Dimitropoulos are still having to turn to the “black” market and /or are daring to self supply because access to and cost of legal products is way beyond their financial reach. This is happening in Qld partly because public hospital policy does not permit its doctors to prescribe cannabis based products.

The rate of approvals has increased substantially since the inception and mushrooming of corporate clinics set up by corporations to move products which were languishing on warehouse shelves because GPs were refusing to prescribe for many reasons. These clinics have the sole purpose of prescribing corporate cannabis based products and have become the gateway to moving them off the shelves to a captive audience of suffering and vulnerable people who are in general, socially disadvantaged by their medical conditions.

It seems these clinics are given “special treatment” in this highly regulated environment as we heard from the **CEO of Medical Cannabis Company THC, David Radford said on sky news** “...we are working with individual State govts to get their approvals (for clinics)... *the clinic is not the same as health clinic that you go through so we are not expecting the same regulatory hurdles...*” <https://www.skynews.com.au/details/5713222826001>

These clinics offer tele-conferencing and face to face consults with doctors who have no prior experience using or prescribing cannabis based medicine in a clinical situation and who have had limited training via educational videos and company backup. Some patients say there is no medical history taken; they were not asked about current medications or allergies and they are being pushed through because the waiting room is full of patients.

MCUA has received many complaints including high cost of consultation fees that vary enormously between clinics – the majority receive no Medicare rebate. On average patients are charged fees of around \$200 to apply to the TGA through an online portal– a process for which there is no fee attached. Costs vary from under \$100 to over \$1000 for the initial consultation and application fees.

Due to the increasing number of complaints about these clinics MCUA is conducting a patient satisfaction survey asking about patient experiences overall with the delivery model set up by the Govt.

Responses to our survey have been consistent throughout with 45% of patients say they are paying \$500 to \$1000 a month for products. Most survey respondents are on Centrelink payments because of their illness and some have got themselves into debt with family or friends, to enable them to purchase the medicine. Almost half of the prescriptions written have not been filled.

Peter Crock, **CEO of the Cann Group** and Chairman of Medicinal Cannabis Industry Australia reinforces this scenario. He said on abc radio recently that: **"All medicinal cannabis is being imported .. that is what is keeping prices high and people are taking the opportunity to make **super profits** on the way thru."**

https://cannabislaw.report/podcast-australian-medical-association-tells-abc-radio-they-still-cant-back-medical-cannabis/?fbclid=IwAR0p6uG6zYomCLxkRpcNOM5MI2GBQtOCmlFRvuIUz_zmKkTeEOn-j6ZIZIM

Although the government figures are claiming 20,000 approvals since 2016, approvals do not equal patient numbers. Many of our respondents say they have had more than one approval with 20% of respondents saying they have had more than 5 approvals. The dissatisfaction rate with the delivery system is sitting consistently at 86% .

Here are some of the patient experiences from our group:

1. One member told us this week that a clinic charged her \$700 in consultation fees and for product for her father to use as palliative medicine for his final days as he was showing an intolerance for conventional end of life drugs. She said **they put u through hoops & lots of bullshit only to deliver 5 days late. They sent us 6 weeks supply of cannabis oil with an expiry date of October 2019; and charged us \$50 to tell us how to administer & dosage amount - only to be told the family GP needs to sign it off before it can be administered.** The clinic have promised the medicine is safe and said they could not be there before Friday (1/11/19) with the proof. Treatment will not begin until the clinic doctor sees the GP because the state owned aged care facility are not allowed to give patients out of date medicine. Meanwhile her dying father is denied medicine that will make his passing easier. She said: **This to me is not acceptable & inhumane, nor is it rectifiable as they are aware time is of the essence for my dad.. not only have they stolen my dad's money but they have stolen his life & that can't be replaced !!**

2. I'm worried my cannabis clinic is taking me for a ride. My appointments initially cost \$100. Then my first batch of tilray was 25mg thc:25mg cbd. I have to buy it in 2 bottles of 25ml otherwise I have to pay an excess of \$50 for shipping. My first script cost was \$633.30 for the 50ml I received. The next time I needed an order it cost \$330.30 for 50ml of the same script. They said that due to its taking off more, the distributor could lower the cost. In 3 months time I had to pay the clinic again to write me up a new script lasting a year this time so it needed to be approved once more by TGA. I managed to get one more script from Tilray for \$330. Recently however they said that they can't get a hold of tilray so they needed to apply for TGA approval again. This time they have me on a different script all together. Althea - capilano 10mg thc:12.5mg cbd at a cost of \$540 for 2 bottles of 50ml. So the maximum of tilray daily was 1.2ml. Where as my new script is 3ml. So what does this cost me to use on a daily basis? Initially when I first started taking it in February this

year at a cost of \$633.30 per 50ml at a dose of 1.2ml daily max. We get an average daily cost of \$15.20. Then it became \$330 for the same. Making it \$7.92 per dose. Now I'm paying \$16.20 daily cost.

3. Yet another said she recently applied for the legal version, knowing full well it was way outside what she can afford. It cost \$200 for initial appointment, \$59 for any subsequent scripts, \$80 follow-up appt, \$59 whenever I have to adjust dose or product, which I was able to afford by making a debt with centrelink, and it seems my case is quite clear-cut and urgent that I got TGA approval within days and scripts for 2 different products. One is \$660 a month, one is \$300 a month. **Needless to say, I cannot fill in these scripts.** I believe it is so discriminatory against people on low incomes;

4. This patient told us I have MS, fibromyalgia, RA, degenerative spinal conditions with previous high impact crush injury to my L5/4/3 and dislocated neck C4/3 Sheurmanns kyphosiscoliosis, crps and high blood pressure, diabetes and copd. I'm going blind because of the MS and have sarcoidosis also. **I am 36 years old and on a TPD pension.** When I broke my back 18 months ago I was looking at being an invalid possibility under palliative care. That simply was not an option as I have kids. So I researched and I found Rick Simpson's cannabis oil recipe and made some Full extract cannabis oil. It is really the only reason I am not wheelchair bound and paralysed. For \$350 I can get an ounce of black market Marijuana and make 250ml of oil. I have been using 50mls (\$70) a month. Before I started on the illegal oil I took 19 pills morning and 20 at night and 10 throughout the day. I'm not taking any opioids any more or pain killers except cannabis oil. It's healed my broken back and dislocated neck where I was told I'd never walk again I'm walking. I sought approval for legal supply through a prescription because I go to hospital regularly due to my lungs and kidneys and they won't let me use my oil in the hospital because it's not "legal" **I now have a script for legal supply. The bottle of oil is waiting at the pharmacy. I cannot afford to pick it up.** It's a thc/cbd blend oil 25ml for \$300. Originally I was told it would be \$159. The doctor reckons that's a months dose. There is no way I can maintain that cost so I have no option but to continue to make my own and run the risk of being raided and prosecuted. **This patient was arrested and charged a month ago when caught by police sending a bottle of home made medicine to a fellow sufferer.**

5 Another said: I paid \$110 in total for two consults, the first with a nurse to see if I met the criteria and the second with a Doctor to go through the application. I was told that I would hear back within a week. After 4 weeks, I emailed them and got no response. I called the mobile numbers that had called me previously and they were disconnected or no longer in service. So I wrote a bad review online and looked into reporting the clinic as a scam. The clinic contacted me and asked me to remove because it was causing some them fuss. In exchange the clinic said they would pay for half of my prescription. The full cost was beyond me, so I agreed. The following week I had to drive 1 & ½ hours round trip to collect it. The pharmacy was not told the payment arrangement and several phone calls had to be made get that sorted. I very quickly worked my way to the maximum dose, without any noticeable impact and was not prepared to spend **\$385 every 5 days** on something that did not work. I was told that I would have ongoing follow up care from the team. I was told that I was not going to have to go through the process alone, that I had the entire team behind me. I never heard from them again.

6 Went to a popular access clinic. I was treated badly with no empathy or compassion by clinic staff because I made comments about the cost of the consultations and product being so high. Then their pharmacist said if you can't afford it, go back to your gp and see what he can give you. What more opioid which I have been trying to get off? I complained

to the practice manager and got nowhere. I have been left without any oil since June. They didn't care that I am not coping and in extreme pain and can't afford to keep paying for consultations, approval applications & the outrageous cost of the oil. Which I feel is very diluted and really not very effective at the low dose. I don't know why I have not been recommended to the compassionate scheme when I have repeatedly told the clinic I can't afford \$450 every 3 weeks on a disability pension and the other high medical costs and medications to buy as well. This system is Not Working and nobody seems to want to help.

MCUA President, Deb Lynch, is currently waiting for a trial date after being arrested and charged for self supply following many attempts to acquire a prescription through Qld Health, whose doctors have been advised not to prescribe cannabis under public hospital policy. Being on a disability pension, there is no way she can afford the costs involved in getting a script from one of these corporate cannabis clinics. This is a small sample. There are many "horror" stories and MCUA has witnessed first hand how the system has failed patients. There needs to be a review with public input and recommendations made to facilitate a quicker more affordable delivery system.

MCUA is currently seeking patients who have been through the legal process to fill in our customer satisfaction survey (<https://surveyhero.com/c/55e2c285>) which will be going to the Federal Senate, via ALP Senator Anne Urquhart along with our current petition to them asking for a full review of the delivery system put in place by the LNP. Cannabis is a herbal remedy and trying to squeeze it into the pharmaceutical delivery model will mean that the hold-ups will continue and prices will remain high as companies who have spent millions to get into the market are not turning a profit. We are asking anyone with an opinion to comment on our petition asking for this review.

Petition link

(https://www.change.org/p/to-the-honourable-president-and-members-of-the-senate-in-parliament-assembled-urgent-review-of-the-medical-cannabis-delivery-system?fbclid=IwAR2wWzqZe-u_VwLoGbCe2IsWM1WWMFDwG2nYnt_0nEkn0djlkrK330Fzq50)