

Senate Legal and Constitutional Affairs Committee
Regulator of Medical Cannabis Bill 2014

Attention: Committee Secretary – Sophie Dunstone

17th April 2015

Dear Sophie,

Re: Committee Hearing Brisbane – Regulator of Medical Cannabis Bill – Wednesday 1 April 2015

Please find attached the proof copy of the Hansard.

I have provided two corrections to the Hansard marked in red.

Please note that with the second amendment. The \$700 figure per day which I quoted was an error. The \$200 per day I stated was a correction to this figure and was to replace the initial figure stated which was incorrect.

The approximate figure of \$200 per day would be based on an approximate highest cost of Cannabinoid medicines per day at any time we were in the USA which would have included the costs of Lindsay's concentrated oil (c02 Oil), infused oils (such as those infused in coconut oil, olive oil), dried cannabis flower for vaporizing and any medibles (medicated edible products) and Cannabis patches.

I would like to expand on this and provide the committee with some detailed information about the type of products that may have been used in Lindsay's regime in the USA throughout last year and the estimated costs of such products if these were to be purchased at a medical dispensary in Washington State.

Co2 Oil – retail rate of \$65 - \$125 per gram (cost would vary depending on manufacturer, strains, organic or non - organic for example). At some time this type of oil was offered at a compassionate rate of \$25 - \$45 per gram or for no cost at all.

Infused oils (these may be in an activated or an unactivated form e.g. in raw form THCA, CBDA acids or decarboxylated/heated with THC active) - \$15 per 4 pack of capsules

Dried Cannabis flower for chronic pain, nausea, epilepsy, appetite stimulation – average of \$10 - \$15 per gram (organic was generally between \$12- \$15 per gram).

Medibles – Medicated edible products dependent on the manufacturer and type of product could range between \$10 - \$25 per item. Lindsay would occasionally have medibles (usually only approx. once per week) such as a muesli bar, brownie bar, savoury snack mix or cannabis infused fruit drink. These could be another additional method of dosing to reach daily dose of cannabinoids for treatment but they would also be helpful for him when travelling long trips to the doctor for delayed pain relief, this was the main reason for use. At one time he would use a medible drink in order to stimulate appetite to be able

to eat at dinner time however most of the time he would vaporize to stimulate appetite to be able to eat as this would rapidly alleviate severe nausea as well.

Transdermal Cannabis Patches - \$15 - \$18 each – These were only starting to become available towards the end of our trip and so we only got to trial these a few times but these patches were available in many different formulations including CBD, CBD:THC, THC Acid & CBN in 10mg dosage and THC Sativa & THC Indica in 20mg dosage.

Juicing – Fortunately we did not have to pay for leaf for juicing but this was difficult to obtain because we did not grow it ourselves (as most people on a juicing regime would grow their own in legal states in USA dependent on personal grow limits for medical purposes) We were only able to obtain leaf for juicing on three separate occasions in Washington State. Dr William Courtney is one of Lindsays doctors in the USA that recommended juicing for him in addition to the oil, vaporisation and terpene enhanced cannabinoid products.

I would be happy to expand if you would like any further information.

I will also be sending through some further information shortly.

Thank you for your time

Lanai Carter

CARTER, Ms Lanai, Private capacity

[16:25]

CHAIR: Could you just tell us who you are? Are you happy to do this?

Ms Carter: Yes, I am happy to do this. I am Lanai Carter, and my son is Lindsay Carter and he is 16 years old. We have been travelling backwards and forwards to the United States over the last year for medical treatment for his brain tumour, chronic pain, epilepsy and nausea, and that treatment has been predominantly cannabinoid medicine. He did start off having an immune vaccine, but in the US, when his tumour appeared to be growing, we were recommended to move up to Washington state where the doctors recommended the use of medical cannabis for him. Within seven weeks of starting that treatment to his tumour had reduced by almost half the size. It had reduced by seven millimetres. We have MRIs back here in Australia that confirm that shrinkage. Last year, on both occasions when we were here for an extended period of time, his tumour started to grow again, and it has just grown again three millimetres in the last three months since we have been home. His seizures increase, but in the US—

CHAIR: Can you explain to us what the treatment is in the United States, bearing in mind that you are not a doctor?

Ms Carter: I can give you very specific information about that. The treatment that he has been recommended in the US was a four to one ratio, which has been proven to be the most effective.

CHAIR: Four to one of what?

Ms Carter: Four THC to one CBD, which has been proven through research done by Dr Sean McAllister in California, where he has been doing research based around brain tumours and breast cancer. It was based on his research and was the recommendation by his doctor in the US. The research that Dr McAllister has done has shown the effects on these specific types of cancers when CBD is administered alone and when THC is administered alone and then when the two are combined together. My son's treatment was in a number of different forms. He would be receiving an oil form ingested. He would also be receiving a vaporised form of cannabis for immediate chronic pain relief and to help with his appetite, because the tumour was causing some wasting and it was causing chronic nausea every day, and also for the side effects of the Epilim that he was recommended here, which was also causing significant side effects such as nausea as well.

CHAIR: Do you know Ms Neville who gave evidence before? Were you in the room when Ms Neville was giving evidence?

Ms Carter: No, I was not.

CHAIR: You do not know her?

Ms Carter: The lady that was here this morning?

CHAIR: Yes.

Ms Carter: No, I do not know her.

CHAIR: It might be useful if both of you could get together sometime and have a chat.

Ms Carter: My son also was being administered cannabis towards the end of last year in a patch form as well. That was not a stand-alone treatment for him. It was like a layering effect. So he would have the vaporisation, to immediately work on his pain levels and to help with his seizures, as well as the oil, and the patches, if we were travelling, for example, as a way he could manage his pain just for short periods of time.

Senator URQUHART: You go to America for the treatment. But when you come back here does he have any of this treatment at all?

Ms Carter: For most of last year he ^{was} ~~had~~ having absolutely none. He did not have any oil last year. We have seen his seizures increase when we comes home. Obviously, that is a big concern to us, and he is not getting seizure reduction on the antiseizure drugs. They are not getting any control of those seizures. So we have started him on some oil since we have been back this time. That has only been for a short number of weeks. The only time he has had a seizure was when he missed a dose.

CHAIR: Excuse me for interrupting. We have a teleconference from Israel. If you would not mind staying, we will come back to you as time permits.

are better for quality and treatment. We have a preference for that, so we are very particular. I would say it is as rare as hen's teeth to find what he need here for his brain tumour. As far as what he needs for his pain, nausea and epilepsy, it isn't a problem to locate it.

Senator DI NATALE: Thank you. That highlights it quite starkly. Let's say you wanted to get the product you get here: have you tried to do that?

Ms Carter: We have not tried to do that but we would love to see an opportunity for that to happen. In fact, what we are trying to do and what we want to do is to be able to work through the special access scheme to get importation of the oil that he needs specifically for his tumour. We would appreciate help with that.

Senator DI NATALE: I imagine you would probably prefer to see the product that you understand works being made available to lots of people.

Ms Carter: Yes, absolutely, and when you can access quality product and you know that it is going to be tested, that makes a big difference for patients.

Senator DI NATALE: That has been very helpful.

Senator BILYK: How much does it cost you to access it when you are in America?

Ms Carter: To source the medicine?

Senator BILYK: Yes.

Ms Carter: For about a gram of oil, in the beginning it was about \$40. When we changed to a more quality concentrate—when I say 'quality', it was just a different, much cleaner extraction method—it was between \$65 to \$120 a gram. But, predominantly, about \$65 a gram would be the going rate for that CO₂ extraction.

Senator BILYK: In a month, how much would it cost you? How much would you need to use for your son?

Ms Carter: If we were having to pay for all of that medicine, about \$700 a day. It would be about \$65 a day for the concentrated oil that he would have in the evening and then, depending on where we were purchasing the rest of the oils that he was having during the day, ~~it could be another couple of hundred dollars.~~ *no sorry it would be a total of \$200 a day*

Senator BILYK: But you said that you did not have to pay for that.

Ms Carter: In the end, we had what they call a compassionate grower who we did start off paying for oil. In the end, they did end up at donating some oil. They knew we had been through a horrific amount of expense travelling backwards and forwards to get treatment for our son and they were able to help us.

Senator BILYK: That was basically the goodwill of the grower.

Ms Carter: It was the goodwill of the grower and a very high quality product.

Senator BILYK: You do not have a prescription to go and get that. You have just sourced that yourself.

Ms Carter: In Washington state, the process is that you would get an authorisation from a doctor or a nurse practitioner or a naturopathic doctor. They would give you an authorisation—I have got one here; it might take me a minute to find it—and it would look like this document here. They all look different, depending on where you are getting them from, but that is the authorisation letter, and you would produce that at a dispensary. The compassionate grower that we eventually found was through a dispensing venue.

Senator BILYK: Was that a pharmacy or someone else?

Ms Carter: No, they have a medical market where you still have to provide your authorisation and the growers would be there, and also some of the companies that manufacture products of different kinds, whether they be edibles or whether they be oils or just the cannabis bud.

Senator BILYK: I understand you have got some documents that you were seeking to table. Is that correct?

Ms Carter: Yes, I have a couple of doctors' letters that I would like to table confidentially.

Senator BILYK: They are copies, is that correct?

Ms Carter: They are copies.

Senator BILYK: I am happy to move that the documents be tabled.

ACTING CHAIR: Is it the wish of the committee that the document be tabled as evidence? There being no objection, it is so ordered.

Ms Carter: Am I able to just read one part of one of these letters?

Senator BILYK: Can we just have a look at them first?

Ms Carter: Yes.