LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH, AGEING, COMMUNITY AND SOCIAL SERVICES

(Reference: Inquiry into exposure draft of the Drugs of Dependence (Cannabis Use for Medical Purposes) Amendment Bill 2014 and related discussion paper)

Members:

DR C BOURKE (Chair)
MR A WALL (Deputy Chair)
MS M FITZHARRIS
MS N LAWDER

TRANSCRIPT OF EVIDENCE

CANBERRA

FRIDAY, 13 MARCH 2015

Secretary to the committee:
Mrs N Kosseck (Ph: 620 50435)

By authority of the Legislative Assembly for the Australian Capital Territory

WITNESSES

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Amended 20 May 2013

The committee met at 9.32 am.

DOWNING, DR KAREN, Private capacity

THE CHAIR: Good morning, everyone, and welcome to this public hearing of the Standing Committee on Health, Ageing, Community and Social Services inquiry into the Drugs of Dependence (Cannabis Use for Medical Purposes) Amendment Bill 2014 exposure draft and related discussion paper.

I have a few housekeeping matters which I need everyone in the room to observe. All mobile phones are to be switched off or put in silent mode. Witnesses need to speak directly into the microphones for Hansard to be able to hear and transcribe them accurately. When witnesses speak for the first time, they each need to state their name and the capacity in which they appear, and only one person is to speak at a time.

Dr Downing, good morning. Thank you for coming.

Dr Downing: Good morning.

THE CHAIR: Can I confirm that you have read the privilege card lying on the table before you and sent to you by the secretary?

Dr Downing: I have.

THE CHAIR: Do you understand the privilege implications of the statement?

Dr Downing: I do.

THE CHAIR: Before we proceed to questions, would you like to make an opening statement?

Dr Downing: I will make a brief opening statement. My name is Dr Karen Downing. I am appearing here as a private citizen and an interested individual. I cannot talk to any of the medical or legal aspects of this proposed amendment—my doctorate is actually in history—but I can talk about the pain and suffering that some people have to go through when they are being treated for medical conditions.

My son was 10 when he was diagnosed with cancer. Cancer in children is particularly aggressive because their cells are replicating on their own, and cancer is opportunistic and it builds on that, so the treatments for children are just as aggressive. The doctors actually say they need to kill the cancer before they kill the child.

The treatment was in Sydney, so it was a complete disruption to our lives for six months while we travelled between Sydney and Canberra, and in both places we spent most of those six months in hospital.

The protocol that he was on, which was a mix of around seven different chemotherapy drugs and intrathecal hydrocortisone injections, had quite severe consequences for his little body. At one stage his mouth and all the way down his oesophagus were ulcerated. This was not part of the cancer; this was part of the treatment for the

cancer. So he could not eat. He was being fed through a tube up his nose, and all of the drugs were going through a tube into his jugular vein. But he could not swallow either, and it was a really distressing time. He was on a methadone drip, which he could activate at any time, but it still was not enough.

We tried all sorts of things. We had a rota of family members who did visualisation and storytelling with him to try and work his way through that sort of pain. At one stage I could tell that the pain itself was causing immense anxiety and fear. I felt that it was getting in the way of the pain management. I talked to his team about that. They agreed with me and they actually used some anti-anxiety medication to lower his level of fear, and then the painkillers started to work a little better.

It just seemed to me at the time that pain management was something that the medical profession did not have entirely sorted out. With all of the other consequences of the treatment, which was itself invasive and painful, you would hope that at least you could help with the pain.

Now, my story has a good ending. That was 15 years ago; he is now 25 and he is well. But I would hate to think that there are people going through similar situations where we could help them and we are unable to at the moment.

THE CHAIR: Thank you for sharing that with us. Perhaps you could tell us what your son was saying to you at that time about the experience. That might be helpful.

Dr Downing: In terms of the pain?

THE CHAIR: Yes.

Dr Downing: Quite early on he slipped into a space where he was in fact sort of unreachable. All he did was play video games. After the first week or so we had very little proper conversation. After we had talked about possible death, and he had told me what he would like painted on his coffin, he did not talk very much about the pain.

I think the body does have quite a remarkable self-preservation mechanism. We talked about it last night. He remembers the whole time. He does not actually remember the pain as such—a bit like childbirth, I imagine. It was the people around him having to witness what he was going through which was far more distressing. I think as an adult he would have been more aware.

THE CHAIR: How long did this go on for, again?

Dr Downing: The best part of six months.

THE CHAIR: So it went on for six months. At the time your child was suffering through this chemotherapy, were you aware of reports of patients overseas being able to access medical cannabis?

Dr Downing: No. It was not raised at the time with us at all and I was not aware of the possibilities of it.

THE CHAIR: Right. And what sort of relief do you think your child might have received if he had had access to medical cannabis?

Dr Downing: I think it may have been a gentler form of sedative, in my not completely limited understanding of the way cannabis works. But one of its benefits may have been to improve appetite, which was a terrible issue for most of the children undergoing chemotherapy. Getting enough calories into them was an ongoing issue.

THE CHAIR: They just did not want to eat?

Dr Downing: They just had no appetite, so they were allowed all the foods that you would never normally give a child, because all they were caring about was the calorie intake. But even McDonalds and chips was not enough to stimulate the appetite.

THE CHAIR: Mr Wall?

MR WALL: Thank you. Dr Downing, I apologise for being late; it was a scheduling problem. Obviously, access to this form of medicinal cannabis would have been something that you would have at least liked to have had the opportunity to use for your son, I gather by the rest of your submission and by your appearing here.

Dr Downing: I would have liked the care team to have had it as a part of their options. I would not have wanted to try to run that gauntlet myself, which I know that a lot of people are currently having to do.

MR WALL: Okay. So you are aware of other families that are going down that road with their children undergoing treatment at this stage?

Dr Downing: Not personally, but I have read about them.

MR WALL: Anecdotal, okay. Part of what we as a community are looking at in line with whether or not we should provide this as a therapeutic option is how patients or carers might access the product. I think there have been a number of proposals as to whether it needs to be looked at through a state grown and supplied type mechanism or whether the patient or the carers are allowed to either grow their own plants or access it by other means. Do you have any thoughts, from a carer's perspective, on what would be most appropriate?

Dr Downing: I think if it is state controlled access, as long as it is cheap and readily available, it may not be an issue, but I can also see some benefits of being able to control the supply yourself, especially for longer term palliative care, and then it might become very expensive.

THE CHAIR: Ms Fitzharris.

MS FITZHARRIS: Thank you very much for coming in today and making your submission. I am particularly happy to hear that there was a happy outcome for you and your family from what must have been a terrible time.

My questions build on my colleagues' questions. As a parent going through an experience like this with your children, particularly when they are so young, from what you have said and from what I have learnt from other parents that I know now that are going through this, they gather a lot of information. You become really well informed about the disease. Did you feel at the time that, in terms of pain management, there was just another option but you did not know what it was; you had a feeling that, as you mentioned, the pain management was not working well?

Dr Downing: I did not have any understanding that there were other options. I was just trying to explore with the care team what options were available. Sometimes just trying to treat the obvious pain was not enough. Morphine was not enough. I have done some reading into long-term chronic pain and I know that there are all sorts of other ways of trying to approach pain, which is one of the reasons we used visualisation and storytelling with him, but that is very tiring.

MS FITZHARRIS: Yes, for you.

Dr Downing: For everybody who is doing it. Yes, it is just if there are other possibilities that are gentler. I cannot say whether it is safer or not but certainly most of the drugs that are used in hospitals have their own side effects.

MS FITZHARRIS: Thank you.

THE CHAIR: Ms Lawder.

MS LAWDER: Dr Downing, along a similar theme, you mentioned that your son was on a methadone drip that he could self-administer. I think you talked about the anxiety and you got the anti-anxiety drugs. Was there a progression there with the methadone? Was it originally administered by someone else and as the pain increased you moved to a self-administered—

Dr Downing: Yes.

MS LAWDER: And was that at your son's—

Dr Downing: When the pain got to a point where they were not keeping up with it.

MS LAWDER: So what came before the methadone? Were there other things?

Dr Downing: I cannot remember all of the different drugs.

MS LAWDER: I am not sure at what point, but when he was coming off the methadone, what was that process like for your son? Was that a difficult process too?

Dr Downing: No more difficult than anything else he was going through at the time.

MS LAWDER: I guess your son was quite likely on a number of other drugs at the same time—medications.

Dr Downing: Yes. There were about seven different chemotherapy drugs.

MS LAWDER: And were there any issues during that time with the mixture of drugs and having to tweak them and change the medications?

Dr Downing: Yes, one called vincristine can have a side effect. We are not exactly sure what it is doing to the body but the symptom is that you start to go bright red from the scalp down, and that happened at least once.

We were also part of a research program that was halving one of the drugs called cyclophosphamide, which is particularly toxic and can lead to all sorts of secondary cancers in the future. So they asked us to be part of that research program. This was completely experimental, and we agreed to be part of that program. He is still seeing his oncologist because they are trying to get as much long-term data about the outcomes of that particular protocol as they possibly can. So he still sees his oncologist.

That was, for us, a very hard decision because they knew that this particular protocol could probably work but it had side effects. This was an experiment. By halving the amount of cyclophosphamide they gave, they could not say what the outcome was going to be, so it was a bit of a step into the unknown. But we were very conscious of the fact that families before us had been making the same sorts of decisions to get to protocols that were becoming more effective, so we agreed to be part of that program. All of it is a bit unknown. I do not think in medicine we ever get to the point where we know what is going on. It is about mediating risk and trying to find the best possible outcome in the given circumstances.

MS LAWDER: You cannot speak on behalf of another person, even your son, but in your discussions with your son have you talked about—touch wood it would never happen—if your son was in that parent position, what he would want for his child?

Dr Downing: Or even himself. Yes. He encouraged me to come along today because he thinks this is a very worthwhile cause to be advocating for.

THE CHAIR: So I take it then that you strongly support the idea that medical cannabis should be available as one of the tools for helping people who may be able to benefit from it and that it should be just part of the rest of the clinical armamentaria available to health teams?

Dr Downing: I do, yes.

THE CHAIR: What do you say to people who oppose that idea?

Dr Downing: I would have to hear what their opposition is based on. Drugs are drugs and the line that we draw between illegal ones and legal ones is one we make ourselves, and that has always shifted depending on where and when you are. I think it is a very reasonable discussion to have and not everybody is going to be in agreement with it whatever you do.

THE CHAIR: And certainly your lived experience with your son has given you a particular perspective which others might not have had to share.

Dr Downing: That is right.

THE CHAIR: Fortunately for them.

Dr Downing: Fortunately for them, yes; you would not wish it on anybody.

THE CHAIR: More questions? Nothing from the table. Is there anything else you wanted to let us know?

Dr Downing: No, thank you.

THE CHAIR: Thank you very much for coming, Dr Downing. It is very much appreciated.

PENGRYFFYN, MR MARC EDWARD, Private capacity

THE CHAIR: We shall recommence this public hearing of the Standing Committee on Health, Ageing, Community and Social Services inquiry into the Drugs of Dependence (Cannabis Use for Medical Purposes) Amendment Bill 2014 exposure draft and related discussion paper. Mr Pengryffyn, have you read the privilege card that is on the table in front of you? It was also sent to you by the secretary.

Mr Pengryffyn: Yes, I have.

THE CHAIR: Do you understand the privilege implications of the statement?

Mr Pengryffyn: I do.

THE CHAIR: Before we proceed to questions, would you like to make an opening statement?

Mr Pengryffyn: Yes, thank you. I am here as an individual private citizen. I am assuming that you have all looked at my submission, which is fairly short. I will not go over the material in that again. I want to add one thing to it. I am here today unmedicated on cannabis, but in one way I am benefiting from its use, in that I have had much better sleep this last week because for the last two weeks I have been using cannabis on a daily basis. One of the effects which I did not put in my submission—and I am not sure why—is its positive effect on sleep for those who have difficulty sleeping.

With chronic fatigue syndrome, I can usually get sleep, but it is not very good quality sleep. With cannabis use, my sleep is much deeper, and that improves my overall health. I am much more lucid today than I would normally be without cannabis, even though I am not on cannabis at the moment. Because I have been sleeping better all week, my mental functioning is much better today than it would be normally. I just wanted to add to the items in my submission that the improved sleep in my case has been dramatic, as well as the effects on pain, energy levels and those things that are in the submission.

I have not needed naps. For the last eight years I have not been using cannabis. I was using it before that medicinally. For eight years, for various reasons, mostly supply problems, I have not been using cannabis. About three months ago the symptoms were getting so bad that I decided I had to start using it again. Normally, without cannabis, my mental functioning would be very poor. I would have real trouble communicating at all. That is one thing I wanted to add to the submission.

Another aspect of the current proposal that I want to talk about is the supply of cannabis. As I said, for the last eight years I have not used it, mostly because of the difficulty of getting a supply. One thing that is neglected in this current proposal is the whole issue of how people who wish to use medical cannabis obtain it. There is a brief mention of growing your own, and that is a good option for those who are able to do it. Of course, for people with health problems, many of them will not be able to grow their own cannabis because they are not healthy enough. They will not have the space. You do need space to grow it, either indoors or outdoors, and there is a cost

involved. If you are going to grow it indoors, the lights are not cheap; the equipment to grow it indoors is not cheap. Even for a couple of plants it is not cheap. People who are struggling with medical bills also might have trouble with that. So growing is an option for some people but not for everyone—possibly not even for the majority of people who want to use cannabis medicinally.

Another option for supply, if they cannot grow, is the black market, which has a whole range of problems—you have black market prices, you have the whole encouragement of an antisocial criminal element, which nobody likes to be involved in. A lot of people may not have used cannabis at all or simply have not used it medicinally or have not used it since they were young. If they develop an illness for which cannabis might be useful, they do not know where to get it anymore. I certainly do not. I have lived in Canberra for about 11 years. When I decided a few months ago that I needed to start using cannabis again because my symptoms were worsening, I did not know where to get it. I went to friends; I went to friends of friends. Nobody was able to help me. I got one small amount from a friend of a friend, just as a sample, but they did not want to sell because they did not want to deal. That is fair enough. I have had to grow my own, which takes time et cetera.

The black market is obviously not a good option. The other thing about the black market is that your choice is limited. Usually you just buy cannabis on the black market and you have no idea what kind of cannabis it is. There are hundreds of different varieties, many with very different medicinal properties. Some are better for sleep, some are better for pain and some are better for appetite. The breeders, particularly in America and Europe, where things are a bit more open, have been combining different varieties to get varieties that are really good for particular medical problems. You do not get that with the black market. That only happens in a market where medical cannabis is at least permitted.

Apart from growing your own and the black market, the only other real source of supply is by way of things that have happened in other jurisdictions such as California, where medical cannabis has been decriminalised or regularised in some fashion. Groups of people have got together to grow cannabis specifically for patients. They are usually small-scale growers. This is to the best of my understanding. I am not an expert on this but I have read about it. Small-scale growers will supply a certain number of patients. In California, they even have medical cannabis clubs or medical marijuana clubs. Patients band together to form a co-op and then source the right kinds of varieties from small growers. That manages to short-circuit the black market, which is a beneficial thing for both the patients and the community.

One particular problem that I know about in California was that the state laws allowed cannabis use for medical purposes but the growing and providing were not quite so regularised. America is different, of course, because you have the federal law versus state law. Many people who were growing cannabis and providing cannabis to medical users were arrested and prosecuted. I am not sure if they still are; I think not, for the last year or two. I am not sure about that. Certainly, they were being prosecuted for growing and supplying cannabis to medical users.

That is obviously an unsatisfactory situation. It is pointless telling people, "You're sick; you can use cannabis but you can't get it. You can't get it legally. You can only

get it illicitly, with the risk of people being prosecuted." That is not a satisfactory situation, obviously.

Another related issue, if you are regularising supply and people are growing their own, is to look at the quantities involved. As I understand it, in the ACT currently you can grow two plants—you are allowed, more or less, to grow two plants—and I think you are allowed possession of 250 grams. I am not sure; that is from memory. That may be okay for recreational use, but medical users will use quite a bit more—not necessarily at one time, but over the period of a week a medical user will probably use much more than a recreational user. They will not use as much at a time, because most medical users do what is often called micro-dosing, where you take very small quantities until you just get to the pain relief or whatever symptom relief it is that you need, and no further. That is the best way to use cannabis medically, because in that way you do not build up a tolerance and have to use more and more.

Over a week a medical user will probably use quite a bit more than a recreational user, on average. With respect to the amount allowed in the current proposal, it would be worth addressing that so that people can possess more and grow more—not necessarily just for their own use but also for the people who are supplying them. For example, if you have a friend who has cancer and they are too sick to grow their own cannabis, you can grow it if you have a garden. They have another friend—I know, because my mother died of cancer 10 years ago—and they get together and talk about things. One says, "Yes, I'm getting cannabis and it's helping my pain a lot, it's helping me with the nausea from the chemotherapy a lot and it's helping me sleep." Somebody says, "Okay, I'd like to try it; where can I get it?" "I'll give you this person's name." Two plants is not going to be enough to supply even one patient, let alone half a dozen, four or five.

Revisiting the numbers of plants that can be grown and the amount of cannabis that can be in the possession of an individual could be looked at with a view to regularising a supply chain for medical users, so that they do not have the anxiety of sourcing a supply of medicine. That is pretty much all I want to say as a preliminary statement.

THE CHAIR: Thank you. Perhaps you could give us some specific examples of how your chronic fatigue syndrome has affected you in your everyday life. Describe an episode for us of how it has severely affected you.

Mr Pengryffyn: Before I started using cannabis again I would get up in the morning with my wife and daughter and make breakfast for the family. We have pets. I would do all of that, and that would wipe me out for the rest of the morning. If I had been conserving my energy well, I might be able to, say, do a load of washing or something like that, but after that I would be wrecked for the rest of the morning. I would have to have a nap for two or three hours. My health has been getting so bad in the last year or so that I have had to sleep for four or five hours during the day.

In the afternoon, when I wake up from a nap, the brain fog is so bad that it takes me half an hour to an hour to be of any use at all for doing anything. I would then do whatever chores needed doing—helping to make dinner, make lunch for my daughter for the next day, for school, wash dishes and do a few chores. But activity is very

limited. I am unable to really concentrate on most recreational activities. I hardly watch any television. I do listen to some music.

Reading takes a lot of work and concentration, just to read a book. The pain is constant. I am unmedicated at the moment and I am in a lot of pain—very bad headaches, muscle aches. All the major muscle groups are constantly sore. The joints are sore. I have mentioned the brain fog. Appetite is up and down and all over the place.

I mentioned in my submission that part of my problem with chronic fatigue, embarrassing as it is, is irritable bowel syndrome. You usually cycle between constipation and diarrhoea, sometimes with an emphasis more towards one than the other. So that creates its own difficulties, as you might imagine. That covers just about everything that I can think of. I am not sure if you want me to go into how cannabis helps with those symptoms.

THE CHAIR: Not yet.

Mr Pengryffyn: Okay. Those are the basics then.

THE CHAIR: Thank you. Perhaps you could tell us what other treatments you have had or medications have been prescribed for you and how effective or ineffective they might have been.

Mr Pengryffyn: Heavens, that is a big question, because this has been going on since I was 20. I was only diagnosed when I was about 33 or so, so for most of that time I did not know what was wrong with me. Just from the time when we knew that it was chronic fatigue syndrome, because before that I did psychotherapy because people thought it might be a mental problem, blah blah blah. None of that was really to the point.

When I was living in Sydney, there was a program being run in Sydney by the rehabilitation service—I think it was the Commonwealth Rehabilitation Service, from memory—that was attempting to get people with CFS back into the workplace through exercise therapy and symptom management. It was a long time ago, so I am having trouble remembering. I think it was like a month-long course—something like that—maybe even longer. It might have been two months or six weeks.

So that was doing targeted, minimal exercise therapy to build up your physical strength, and then also teaching you strategies for dealing with the symptoms such as how to deal with pain, how to deal with the fatigue, how to deal with the brain fog. So I did that, and it was good and worthwhile doing, but it did not get me back into the workplace. I tried—Lord knows I tried—but that did not work.

The medical profession cannot really offer a lot—pain relief; that is about it. I went to see a psychiatrist who also specialised in the treatment of illnesses in the very elderly. He was recommended to me because the physical condition of people with CFS is often like people who are very, very old. He was recommending, again, an exercise routine, starting at really minimal levels to try and build up my basic fitness again. And that was good for a while, but I got so sick eventually that I just could not keep

up the exercise routine. At that point I was using cannabis, so the exercising came much more easily, but it was when I stopped using the cannabis that the symptoms came back, so I found it pretty much impossible to keep up an exercise routine.

There are other things that you read about. The chronic fatigue websites have thousands, probably, of things that people say: "I've tried this and it helped." Whether it really helped them or whether their symptoms were improving anyway and they thought it helped, who knows? I have tried any number of those. I have tried ice baths, which just gave me headaches. Lord, I cannot think now. What are the other things I have tried? Various combinations of medications. I take antidepressants. They are usually prescribed for people with chronic fatigue syndrome because of the depression that goes along with it. I did not mention depression before, sorry.

I tried thyroid hormones because a friend of a friend from the UK with CFS had tried taking thyroid hormones and she thought it had done her a lot of good. It did not work for me at all. Those are a few. I cannot think of any others. There were undoubtedly others over the last 20 years or so, but those are the ones I can think of.

THE CHAIR: Mr Wall.

MR WALL: Thank you, chair. Thank you for sharing your experience, Mr Pengryffyn.

Mr Pengryffyn: You are welcome.

MR WALL: Obviously, supply is going to be a big issue if we do go down this road. Just to put a bit of context around it, from your own experiences how much do you think an individual would need on a weekly basis? I know it is going to depend on the dosing, but from your experience what sort of quantity?

Mr Pengryffyn: From my own experience, on a weekly basis—I do not normally weigh it so I am not sure in terms of weight. Before I answer the question, dosage is not the only issue. Different cannabises have different potencies as well and a lot of the ones that are useful for medical purposes have actually a lower overall potency. So you might need more of the actual plant material than you might of a recreational variety because it has been bred for some of the other cannabinoids like CBD. I cannot remember all the others; there are 85 of them. So it is what variety it is that you are using.

I am trying to grow my own at the moment. For personal use, I would say something like about eight plants—eight or 10. Although you could get away with fewer plants if they were a large growing variety that was highly productive, many of the plants that you want to grow are of a smaller variety. They only grow this big, so each plant produces relatively small quantities, but you might want to grow a whole bunch more of them. The smaller ones tend to have a shorter life span.

MR WALL: Just for Hansard's benefit, the height you are suggesting is about 40 centimetres.

Mr Pengryffyn: The height I am suggesting is about 40 centimetres, sorry. I would

say eight or 10 plants would be probably enough for just about anybody, even of the smaller variety of the least productive types.

The other thing is that if you are growing it yourself, for yourself, you will want to grow plants that produce seeds. Commercial growers and black market growers use what are called feminised plants. They do not produce seeds. They just produce the female flowers—no males—because the most resin, which is where all the cannabinoids and the terpenoids, or mostly the cannabinoids and terpenoids are, is found there.

The plants without seeds produce a lot more resin, but obviously you cannot breed from those because they have not produced seeds. If you are growing for yourself, unless you want to regularly buy seeds—which produces, of course, its own problems—where do you get the seeds from? If you want to grow from your own seeds you will be growing plants that are less productive by nature of that. They have to be less productive so you will need more plants to produce the same amount of medicinal chemicals.

So I would say eight or 10 plants. At a guess, in terms of how much per week—Lord, again, as I say, I do not weigh it so I do not know the weight.

MR WALL: Eight to 10 plants gives a good indication of the—

Mr Pengryffyn: Yes, because the other thing is that if, for example, you have got cancer you know you have got chemo coming up. You know you are not going to want to do any work in the garden for six months or three months or four months, so you want to grow a large quantity to last you over the time until you can get back out in the garden. That quantity might seem high but that is for a year's supply, say. If you are growing outside you have only got one crop a year. You cannot grow it in winter here in Canberra unless you grow inside. Outside you can only grow one crop a year.

THE CHAIR: Ms Fitzharris.

MS FITZHARRIS: Thank you. Thank you, Mr Pengryffyn. I have a black thumb, not a green thumb. One of the propositions put to the committee is that people can grow their own.

Mr Pengryffyn: Yes.

MS FITZHARRIS: You sound very informed about that.

Mr Pengryffyn: Moderately.

MS FITZHARRIS: But it also sounds like a fair amount of work for you to do—

Mr Pengryffyn: Yes.

MS FITZHARRIS: as opposed to being able to purchase any over-the-counter medicine which you know you can trust and has come through a supply chain that you

trust and you know something about.

Mr Pengryffyn: Yes.

MS FITZHARRIS: But it sounds to me like it is quite a lot of effort for you to grow. Like you say, for people going through other forms of treatment—parents of children, for example, who might still have to go to work—actually growing your own plants, particularly in reasonably large quantities like eight to 10 to be available every week, is a fair amount of work.

Mr Pengryffyn: You would not need eight to 10 a week.

MS FITZHARRIS: You just need to grow them.

Mr Pengryffyn: Eight to 10 plants for at least half a year's supply, maybe a year.

MS FITZHARRIS: Could you put a finger on how much time you would need to spend?

Mr Pengryffyn: If you are growing outside, once you have got an established garden you probably would not need to do much more than about 10 minutes a day, on average. There will be, of course, as with all gardening, periods like your planting season and your harvesting season when there is a lot more work involved.

I had to prepare a garden bed. If I had not had a free gift of cannabis three months ago from the friend of a friend I would not have been able to do that, probably. I may have been able to, but it would have taken me a whole year rather than just a month because the physical effort involved would have just been too much for me.

So growing indoors or growing outdoors is probably about the same. You do not need to spend much more than about 10 minutes a day. You do need to know what you are doing. They are not hard plants to grow, particularly. They grow in the wild all over the world just about. But to get the best results for producing medical quality you do have to put in some work. You have to keep up the water, you have to give them the right nutrients, space them out properly and prune them if they need pruning. They are not high skills, but they do take some effort and time. The physical effort is generally moderate, interspersed with harder work occasionally. If you are setting up an indoor growing room you have got to move plants around. That is lifting and carrying, and they are heavy. For frail people that is not possible, but somebody could help them.

MS FITZHARRIS: And I take it you smoke it for—

Mr Pengryffyn: No, I do not. I have done in the past. I use an inhaler. You can also eat it, of course. It is problematic getting a micro-dosage with eating. Cannabis butter is the usual way. You heat it at a very low temperature in butter, and that extracts the cannabinoids and the terpenes into the butter—they are fat soluble—and then you use the butter in cooking or you spread it on a bit of cracker or something to use. But dosing with that is really hard because it is just hard to be precise about how much you are getting when eating.

Inhaling is good. You are not getting smoke. We know that smoke has harmful chemicals in it, although there is some evidence to show that cannabis itself has anti-cancer properties. The current data seems to suggest that smoking cannabis is much healthier than, say, smoking tobacco, because the nicotine itself is a toxin and, of course, cannabis does not have that toxin. And there are other things they put in cigarettes that are probably not good for you as well.

That said, most health professionals, or people advocating medical marijuana, recommend inhaling. An inhaler, if you do not know, is a device—they are getting quite small now—that has a heating coil. The best ones have a ceramic heating coil because they just give a steadier temperature. It either blows or you suck air through the coil at a sub-combustion temperature. The cannabinoids vaporise at different temperatures. Most of them are all vaporised by about 220 degrees Celsius. About everything vaporises by that temperature. That is quite a lot below combustion. So you are not burning it; you are just vaporising off the medical compounds and inhaling that. You have got a tube, usually, that you inhale through, either a glass one or a medical grade plastic one—vinyl, usually, I think they are.

That is how I use it, because it does not produce the smell; it does not produce the burning by-products which are probably not good for you. It takes a bit longer. It takes longer to inhale a quantity of cannabis than it would to smoke it. It takes probably three to four times as long, but you are only talking about five minutes. It is not a big deal. Certainly it smells less and it is a lot less fuss and bother.

MS FITZHARRIS: When you find you need to use it, how many times a day would you find you need to use it?

Mr Pengryffyn: It depends a bit on activity. In the last couple of weeks I have been using four, five or even six times a day. Generally the effects of inhaled cannabis last for about two hours. For ingested cannabis, from eating it, it lasts for much longer—about four hours. So although it is harder to get the right dose, a lot of people prefer to eat it, just because it lasts longer and gives you a longer effect.

I might use cannabis about every two hours, if I have a lot to do. I have eight years of household chores backed up, so in the last three months I have been trying to catch up, without making myself sick again. I have been pretty busy, so I have been using quite a lot. Once things settle down a bit and I have a bit less on my to-do list, I might taper that off a little. I will have to experiment and see. So it is about every two hours at the moment, in the last two weeks. But that is more than normally, probably.

MS LAWDER: In your submission you spoke about how you found cannabis has been beneficial to a greater extent than some of the prescription drugs that you have had.

Mr Pengryffyn: Yes.

MS LAWDER: I do not want to invade your privacy, but have you discussed it with your doctor and has it reduced the amount of prescription drugs that you take?

Mr Pengryffyn: Not prescription medicine, no. But if I am using cannabis I can stop

my pain medication entirely. Doctors are reluctant to give anything except over-the-counter pain medication to CFS sufferers because we are on it forever, pretty much. I have a form of CFS that does not seem to be relapsing at all. Some people have it for two or three years and then they lapse and they are more or less better. Usually, there are some residual symptoms, but they are more or less better. In my case, it is not; I am just getting gradually worse. Because it is a long-term, chronic thing, they are reluctant to give strong pain medication because most of those have addiction problems and other health issues.

In terms of over-the-counter medication, I have been taking the maximum recommended amount of paracetamol and Nurofen every single day. If I do not take them, I suffer. This week I stopped taking pain medication on about Tuesday. I thought, "I don't think I need it anymore." This morning is the first time I have taken it again, because I have not used cannabis this morning, and I am in a lot of pain. Paracetamol and Nurofen have blunted it a little bit, but nothing like to the degree that cannabis does. If I was using cannabis, I would not be wincing, because I would not be in this amount of pain. Does that answer your question?

MS LAWDER: Yes, thank you.

THE CHAIR: Could you tell us what sort of difference to your life a legalised regime might make?

Mr Pengryffyn: Given that I am currently defying the law, technically, I would prefer not to. I would prefer not to defy the law. It would reduce the anxiety that goes along with using something that is technically illegal, even though it is a little bit tolerated. The uncertainty is quite unsettling, although not so much for me personally. Before I was married and had a child, I did not worry about it quite so much, although it was always a concern. Is a cop going to knock on your door because you are using a medicine? Can you get a supply? I have something big on next week; I am running low; I have not been able to grow any. Can I buy some cannabis to see me through this next week, because I have a lot to do? Those kinds of anxieties, if they could be relieved, would be a great weight off one's mind.

Having a wife and daughter as well adds extra considerations because if I were to get arrested, that would also affect them, and I do not want that. That is part of why I have not used it for eight years, until just before Christmas last year. Part of my consideration for that was because I had a wife and a child, and I did not want to risk any legal problems that might also involve them. As I said, three months or so ago the symptoms just got so bad that I was useless; I could not do anything, and I had to consider using again.

If it did not have the legal risks involved, I would feel much more comfortable about that. I have told my daughter what I am doing and why I am doing it, because I do not believe in keeping secrets like that. I am growing plants; she can see them. She says to me, "What are those?" I am not going to lie to her. She knows about alcohol and tobacco and that these are things that some grown-ups use but that are dangerous. She is very anti-alcohol. Hopefully, she will keep that up. So I have explained that to her. But I really do not want that concern for myself and I do not want it to be affecting my family—the concern about legal repercussions because I use a medicine.

MR WALL: Mr Pengryffyn, do you still rely on sources of cannabis other than what you are capable of growing yourself?

Mr Pengryffyn: Not at the moment. I do not know of any other sources in Canberra. I do not know of anybody in Canberra. I have lived here for 10 years, but because I have been so sick I do not get out much.

MR WALL: You are obviously going down this road because you find benefit from it regardless of the legality?

Mr Pengryffyn: Yes.

MR WALL: Ultimately, you are aware of other people that are doing the same, but are there many cases you know of where people are not willing to try this because of—

Mr Pengryffyn: Are not willing to?

MR WALL: Are not willing because of—

Mr Pengryffyn: Not in the ACT, no. I have read cases about that, in other places. But I do not know of anyone in the ACT. I do not have a big social support network in the ACT, because I just have not been well enough to get out and meet people. I have a few friends that I see occasionally, mostly friends of my wife that I am also friends with. Because I have been so ill I have not been able to socialise while I have been living in Canberra.

THE CHAIR: Thank you for your evidence, Mr Pengryffyn, and your submission. You can get a copy of the transcript next week from the committee secretary. Thank you very much for coming in today and sharing your story.

Mr Pengryffyn: You are very welcome. Thank you for having this committee inquiry.

CHRISTODOULOU, MR NICHOLAS, Legal Intern, Law Reform and Social Justice Program, Australian National University

THE CHAIR: Mr Christodoulou, could you confirm that you have read the privilege card that is on the table before you? It has also been sent to you by the secretary.

Mr Christodoulou: Yes, I have.

THE CHAIR: Do you understand the privilege implications of the statement?

Mr Christodoulou: Yes, I do.

THE CHAIR: Before we proceed to questions, would you like to make an opening statement?

Mr Christodoulou: Yes, I would. Firstly, the proposed model in the Drugs of Dependence (Cannabis Use for Medical Purposes) Amendment Bill 2014 does not attempt to set up a governmental system for selling or supplying cannabis to people. Instead, it permits individuals suffering from chronic pain to use, cultivate and self-medicate with cannabis. It does not address the commonwealth Therapeutic Goods Act framework or commonwealth importation legislation, or anticipate Australia's international obligations, particularly under the UN Convention on Narcotic Drugs 1961.

The 2014 draft appears analogous to draft legislation proposed in 2004 which attempted to amend the ACT Drugs of Dependence Act 1989. The 2004 proposal permitted medical practitioners to prescribe cannabis and allow individuals to apply to the Chief Medical Officer for approval to possess and use cannabis and essentially self-medicate.

In addition to possession and use, the potential amendments propose that an individual could apply for a licence to cultivate cannabis for medical purposes. The draft legislation also includes various new clauses providing exemption from prosecution for persons using or cultivating cannabis that have been issued with a licence. The proposal was rejected for, among other things, not being developed in accordance with evidence-based medical or treatment guidelines and for ignoring Australia's framework for the regulation of therapeutic goods.

In relation to Australia's international obligations, the 1961 convention permits the production and manufacture, export, import, distribution, trade in, possession and use of a prohibited drug as long as the abovementioned is deemed necessary for a particular country for medical or scientific purposes. There is no definition in the 1961 convention of what medical or scientific purposes are. However, international legal commentary suggests that the term is sufficiently broad to include the prescription or certification of cannabis for medical purposes.

However, most relevant to the current draft proposal, article 28 of the 1961 convention specifies that cannabis cultivation must adhere to the same controls as opium production, found in article 23. Article 23 of the 1961 convention indicates that cultivation licences would need to be granted and land where cannabis can be grown

specified. Furthermore, the cultivators are required to deliver their total crops to a specified government agency and the agency would then purchase and take physical possession of the cannabis crop. Therefore, although it is technically possible that the 2014 proposal could be implemented in ACT legislation without violating international law, it would be nonsensical for the ACT government agency to be purchasing numerous small amounts of cannabis crops of patients and then selling it back to them. It is probable that article 23 of the single convention was designed for large-scale manufacturing and not small quantities of cannabis for individual use.

Additionally, not only are there international obligations that are of concern in the current proposal but it appears that commonwealth legislation has been overlooked, such as the Therapeutic Goods Act—the TGA—mentioned earlier. Because section 157 of the ACT Medicines, Poisons and Therapeutic Goods Act 2008 states that commonwealth therapeutic goods laws apply as law of the territory, the TGA will be decisive in relation to any medicinal cannabis policy in the ACT. The TGA creates the Australian Register of Therapeutic Goods—the ARTG—which lists all therapeutic goods which are approved for supply in Australia. But, except for some limited exceptions, only those goods included on the register can be legally marketed in Australia. Therefore, in order to supply and use cannabis medicinally in the ACT, registration on the ARTG would be essential.

There are a few problems with registration on the ARTG. Firstly, registration of crude cannabis can only be achieved on application by a pharmaceutical company. This is unlikely because of the difficulty with patenting cannabis in its crude form, making it less attractive as a viable product for a pharmaceutical company. Secondly, there would be minimal incentives for businesses to manufacture cannabis due to the ACT's limited population and limited market size. Thirdly, drugs that are approved on the ARTG are based on the product's quality, safety and efficacy. Because smoking is currently the preferred method of administration for most users, the associated risks may prevent cannabis from gaining approval on the ARTG.

However, the TGA is not a complete barrier, and there are possible schemes that the government could follow. For example, firstly, they could rely on the Australian orphan drug scheme for drugs that are not commercially viable. That is under the Therapeutic Goods Regulation 1990. This basically absorbs some of the costs associated with production and retail of medicinal cannabis. Secondly, they could rely on section 19(1) of the TGA, which provides exemptions for special and experimental use so that individuals with permission of the secretary to the department of health and aged care can personally import specified therapeutic goods that are not registered goods for use in the treatment of another person. Thirdly, they could rely on section 19(5) of the TGA, which permits a specified medical practitioner, with the permission of the secretary, to supply therapeutic goods to be used as treatment.

All these options are probably not feasible for the ACT because they are dependent on pharmaceutical companies or the permission of the secretary, which is susceptible to change. Alternatively, and in my opinion probably the most feasible, is that the ACT can amend section 157 of the ACT Medicines, Poisons and Therapeutic Goods Act 2008, dissociating the ACT from the TGA and thereby creating the possibility of a separate therapeutic register in the ACT that provides specifically for the registration of medicinal cannabis. This will be similar to the commonwealth bill which is

currently before the Senate which proposes to establish a regulator of medicinal cannabis who can approve products to be listed on the register of regulated medicinal cannabis products.

The register would operate independently from the TGA and, accordingly, the TGA would not apply for things done in accordance with licences or authorisations issued by the new regulator of medicinal cannabis. Furthermore, the commonwealth bill addresses cultivation and potential international ramifications for not adhering to the 1961 convention, particularly articles 23 and 28. It offers a more viable option for reform than either the 2004 or 2014 ACT bills, because it overcomes barriers associated with the TGA and addresses Australia's international obligations.

A basic breakdown of the model that is the most viable option for the ACT and that would conform with Australia's international obligations and domestic legislation is as follows: firstly, the crop should be grown in the ACT, in designated places, with the ACT government's authority and, as soon as the harvest of the cannabis crop takes place, the government must take possession of the crop. The ACT government then assumes the role of wholesaler and distributes the product to a retailer who can then provide a dispensary to patients with a doctor's prescription.

Lastly, there are products that have been developed by pharmaceutical companies in an attempt to circumvent health risks associated with smoking cannabis, such as oral tablets and mouth sprays which contain cannabinoids. However, these alternatives are seen as impractical because of the unreliable effects that oral THCs produce and the difficulties in taking oral medication when suffering from nausea or vomiting. Furthermore, the mouth spray appears to work; however, it costs between $500 and $800 a month, an insurmountable financial barrier for patients and carers, and it usually leads to many patients reverting to smoking cannabis.

As previously discussed, smoking crude cannabis should not be seen as an appropriate medicinal method of administration. However, an alternative pulmonary method of administration is currently available—I think we just heard about it, actually—in the form of a vaporiser. A vaporiser heats the cannabis material to a high temperature without causing combustion of the plant material but instead creates a vapour which can then be inhaled. The method distributes cannabinoids rapidly into the bloodstream, thus limiting the prospect of excessive or insufficient dosage while circumventing noxious by-products associated with smoking. This means that patients can sustain the advantages of pulmonary administration and have access to an affordable product.

THE CHAIR: I take it, therefore, that you consider the 2014 bill to be significantly flawed?

Mr Christodoulou: I do, yes.

THE CHAIR: Do you think there is any way, given your analysis, that a grow-your-own approach could be utilised?

Mr Christodoulou: Not if you want to adhere to Australia's international obligations, because it specifically says in relation to cannabis that it has to be controlled by the government. The only way that you could do it—but, as I said, it is nonsensical—is

by a patient growing their own with permission and a licence from the secretary or an authorised person. But then the government, as soon as the crop is grown, according to the single convention, has to take control of that crop. It would then sell that amount back to the patient. It just seems to be a backward way. I think it would be easier if the government took full control and, as they do with opium in Tasmania, just grew it. Once they got possession of the crop after harvest, they would act in the role of wholesaler and then distribute it to dispensaries where patients could pick it up, with a prescription from a doctor.

THE CHAIR: What you are proposing, in essence, is something similar to the Dutch bill.

Mr Christodoulou: Which scheme?

THE CHAIR: The scheme that is employed in Holland for distribution.

Mr Christodoulou: I think we have to grow it and cultivate it in the ACT. Importing it is doable, but if you grow it within the ACT, you can circumvent all the commonwealth importation legislation. Also, it would probably be a lot cheaper for patients in the long term.

THE CHAIR: Do you foresee any other legal obstacles to the scheme which you have proposed?

Mr Christodoulou: The only obstacle, as I have mentioned, is the TGA, the Therapeutic Goods Act. As I said, I think we have to dissociate ourselves from the TGA and, as with the commonwealth proposal, create a separate equivalent TGA that just deals with cannabinoid products.

THE CHAIR: So that would be a requirement, to amend ACT legislation?

Mr Christodoulou: Yes.

THE CHAIR: And the government sanction specifically to grow it in the ACT would cover off on the international obligations?

Mr Christodoulou: Yes.

MS FITZHARRIS: Do you know whether, if it was grown in the ACT, there would be any legal impediments to that being provided to other states and territories should they develop, or vice versa—for example, a grower just over the other side of the border? What would be the legal—

Mr Christodoulou: I am not 100 per cent sure, because I only really looked at the ACT.

MS FITZHARRIS: The importation to Australia through the customs legislation, that does not—

Mr Christodoulou: Yes, as long as you get permission from the secretary or

authorised person, it is okay to import cannabis. But you would have to have a close look at other states' legislation just to make sure that you would not be breaking any state or territory laws. If it was legal for medicinal use in the ACT, I could see that there would be problems with distributing it to New South Wales or wherever, without an extremely close look at their legislation.

MS LAWDER: When you talked about dissociating from the Therapeutic Goods Administration, does that mean you have to completely dissociate or just on that particular drug or issue?

Mr Christodoulou: Section 157 of the Medicines, Poisons and Therapeutic Goods Act says that the law of the TGA is applicable in the ACT. That, to me, is the main barrier—the TGA. If you could separate that—

MS LAWDER: I understand, but does that mean for everything?

Mr Christodoulou: No, just the cannabinoid products; only for that. I think we can keep the work side by side.

MS LAWDER: So we do not have to do our own thing—

Mr Christodoulou: No, just for cannabis.

MS LAWDER: At the start of your recommendation on page 10 you state that if the ACT "is inclined to enable the medical use of cannabis, a viable legal framework needs to be established"—"a flexible interpretation".

Can you talk to me a little bit more about what that might mean?

Mr Christodoulou: In America, Colorado, Washington state and Washington DC have now completely legalised recreational cannabis as well as medicinal cannabis. The Americans take a flexible interpretation to the single convention. There has been quite a lot of criticism that they have gone too far. That is what I am saying; so there is a limit to the applicability. We have to make sure that we do not go too far and that it can only be for scientific or medicinal purposes; anything else would be a breach of the international obligations for Australia.

MR WALL: One of the options that the exposure draft purported was that ultimately the conditions that would enable someone to access medicinal cannabis would be set by regulation, which generally takes two ministers and cabinet to sign off on. Do you think that is a reasonable enough safeguard to stop what you might say is "creep" to lesser conditions, or do you think there need to be further safeguards in place to ensure that the intent of the scheme remains purely for chronic illness and chronic pain relief?

Mr Christodoulou: As opposed to what, sorry?

MR WALL: The proposal is that the conditions would be stipulated by regulation, and you spoke about the liberalisation of those laws in California, Washington state and Washington DC. What measures do you think the ACT should look at, consider

or potentially adopt to prevent ultimately that going directly to recreational use?

Mr Christodoulou: It is a tricky one, really. All I can say is there have been studies that I have read, which I have written about in a different paper, that show that recreational use does not go up in states like Colorado and Washington. This is a 10-year study. It is not even Colorado or Washington; it is just in places in America where the drugs have been legalised for medicinal use. The recreational level has not gone up. I would hope that what you are suggesting is enough of a safeguard. I would hope that is adequate, but I do not really know.

MR WALL: Ultimately, you envisage with the scheme that it would be a physician, a doctor or a specialist who would be prescribing—

Mr Christodoulou: I think so, yes.

MR WALL: what would ultimately be a controlled product?

Mr Christodoulou: Yes, just like any other prescription drug.

THE CHAIR: The TGA already approves a couple of synthetic cannabinoid products. Would your proposed change to the ACT legislation draw those out of that TGA approval?

Mr Christodoulou: I think it is fine. I think they are fine if you can afford them. But that is the problem. I think it is just the sheer expense of these products. The main one is the inhaler that they use for MS. As I think I said, it was $600 to $800 a month, which is just excessive. I feel one of the main reasons that is preventing crude cannabis from being placed on the ARTG is that it is difficult to patent this natural product. I feel we are just trying to reinvent the wheel.

MS FITZHARRIS: With the $500 or $800 a month, that is because it is presumably not on the pharmaceutical benefits scheme?

Mr Christodoulou: I do not know.

MS FITZHARRIS: Which would make it significantly cheaper to the consumer.

Mr Christodoulou: Yes.

THE CHAIR: Just returning to the issue that Ms Fitzharris alluded to before, we know that New South Wales is also going through the process of considering some form of legislation to enable medical cannabis. We are a small jurisdiction.

Mr Christodoulou: Sure.

THE CHAIR: We are surrounded by New South Wales. The questioning around cross-border importation would probably be of interest to the government if this was going to be something that was going to go forward. Do you see anything within the constitutional freeing of interstate trade that could be helpful there?

Mr Christodoulou: It is difficult. I have not looked into it so I cannot really comment, to be honest. As you say, because the ACT is quite small, I would hope that it would bring some money into the economy from people travelling from other states to the ACT. But, again, I do not really know what the ramifications would be once they take that cannabis product or what have you outside the territory.

THE CHAIR: So what you were saying previously is that if the New South Wales government, for instance, grew it and our government got it off them, that would be okay under the international conventions.

Mr Christodoulou: If it is legal in New South Wales, are you saying?

THE CHAIR: If you have similar legislation in both jurisdictions, would the ACT government be able to buy it from New South Wales?

Mr Christodoulou: And not breach international obligations. That would be fine.

THE CHAIR: Or any commonwealth—

Mr Christodoulou: As far as I know, that should be fine, yes.

THE CHAIR: Thank you. Or vice versa, indeed.

Mr Christodoulou: I think that would be okay, yes, but I would have to look a little bit more.

THE CHAIR: If you do not mind doing that and providing another submission to the secretary, that would be very much appreciated.

Mr Christodoulou: Yes, no problem. No worries at all.

THE CHAIR: Are there any more questions? I think we are all done. Thank you very much, Mr Christodoulou. You can get a copy of the transcript next week from the secretary. Thank you for the time and the analysis that you have put into this. It is much appreciated.

Mr Christodoulou: Thank you very much.

Sitting suspended from 10.53 to 11.03 am.

BEALE, MR GRANT EDWARD, Private capacity
BEALE, MRS KATHY LORRAINE, Private capacity

Evidence was given via teleconference.

THE CHAIR: Good morning, Grant and Kathy.

Mr Beale: Good morning.

THE CHAIR: Welcome to this public hearing of the Standing Committee on Health, Ageing, Community and Social Services inquiry into the Drugs of Dependence (Cannabis Use for Medical Purposes) Amendment Bill 2014 exposure draft and the related discussion paper. Can I confirm that you have read the privilege card which has been sent to you by the secretary?

Mr Beale: I have.

Mrs Beale: I have.

THE CHAIR: Thank you. Do you understand the privilege implications of the statement?

Mr Beale: Yes, I do.

Ms Beale: Yes, I do.

THE CHAIR: Before we proceed to questions, would you like to make an opening statement? When you speak for the first time could you state your name and the capacity in which you appear, please.

Mr Beale: Certainly, yes, I do have an opening statement, thank you.

THE CHAIR: Please proceed.

Mr Beale: My name is Grant Beale and I am a private citizen from Brisbane.

Firstly, I would like to sincerely thank the committee for granting me this special opportunity to provide some evidence by sharing with you my family's personal experiences and beliefs with respect to seeking support for the legalisation of medicinal cannabis. I am 48 years of age. I am a husband and father of three children. I have never taken illicit drugs and I have always been a non-smoker. I nor anyone from my family has ever had any criminal convictions and I have always held a good standing within the community.

With reference to my submission, I also included a personal letter dated 23 June 2014, which I sent to over 200 politicians on all sides of Australian politics, supporting my concerns about the critical need for medicinal cannabis being made available to a wider range of people who are chronically sick, and not just exclusively for the terminally ill. This is important, folks, as we need to be mindful that we have an ever-aging population and our children depend on the wellbeing of parents, uncles, aunties

and grandparents to ensure they are cared for and nurtured in the best possible environment. Accordingly, we need to ensure medicinal cannabis is accessible by chronically sick people too.

I am very grateful to Greens senator Dr Richard Di Natale and Mr Shane Rattenbury, who both acknowledged and supported my plea and personal situation, showing great understanding and compassion. For that I sincerely thank them.

If I may, I would like to start my personal story by respectfully asking you all to ponder for a moment a very fundamental question: what options does a human being have who is suffering from an unmanageable chronic illness when they have unfortunately been informed by their medical experts that they have reached the end of the pharmaceutical road? What can they do? Please, just give this some serious thought: what can they do?

Before I continue to elaborate on the specifics of my family's issues, I must mention that we have undertaken an extensive amount of personal research for over 18 months into the damaging effects on the human body from long-term use of pharmaceutical drugs, including chemotherapies and opioids, and we have looked closely at various herbal based therapies as an alternative treatment. We have also read and watched hundreds of videos and stories about what others have done to try to manage their chronic illness, and you would guess right: we always end up back to medicinal cannabis being the holy grail for treatments for such conditions.

Therefore, after considering our family's situation very carefully, we felt more than confident with the extensive research we had done on medicinal cannabis. This included attending the medicinal cannabis symposium held in Tamworth last year, thanks to the dedication and commitment of Lucy Haslam and her family on behalf of their young son, the late Dan Haslam. We have also educated ourselves by attending medicinal cannabis workshops and consulting online with medicinal cannabis experts from both here in Australia and the USA and directly speaking with others who had used medicinal cannabis with great success, just like one of our friends here in Brisbane. She was diagnosed with terminal stage 4 cancer last year and given a survival rate to the end of the year. However, after taking medicinal cannabis oil for many months, by September a follow-up PET scan medically confirmed all her cancer was gone. I have a colour copy of her scan with me here now.

The more we researched, the more evidence we uncovered and, again, our personal research was further reinforced by the unprecedented positive results young people were achieving using medicinal cannabis oil to stop the daily suffering from hundreds of uncontrollable tonic-clonic seizures here in Australia that pharmaceutical drugs could not manage but came with grave side effects. Furthermore, we also learned that ironically the US government department of health holds a number of patents for medicinal marijuana as an antioxidant and neuroprotectant for a variety of serious health issues. This, again, reinforced our beliefs that medicinal cannabis does indeed possess valuable medicinal healing properties. All this compelling evidence in our minds was nothing short of overwhelming and therefore we finally made the decision ourselves to obtain some medicinal cannabis tincture from a trusted source to try ourselves.

Well, the results speak for themselves. As outlined in part of my letter dated 23 June, my 71-year-old mother, who has always been a non-smoker and non-drinker, had been battling meningitis for 3½ half years, diagnosed as having been brought on by sarcoidosis; that is, her own immune system fighting itself. During this time she unfortunately contracted shingles in three nerves. This included her right arm, hand and fingers and this soon developed into postherpetic neuralgia, PHN. PHN is an excruciating nerve pain condition, and Mum has now been suffering this for four years, with pain so debilitating at times she had seriously considered having her right arm amputated.

As part of the ongoing attempt to manage her excruciating pain, she continues to use electrical therapy for nerve stimulation several times every day in the form of a TENS machine taped to her right hand and arm. Previously at night it had been a great challenge for her trying to get an acceptable amount of sleep, so part of her bedtime routine would be to lay her arm wrapped inside a plastic bag filled with crushed ice to try and alleviate or relieve the terrible burning pain of nerve damage while she slept.

However, her hypertension specialist advised that she stop the ice bathing due to it causing her blood pressure to skyrocket, which in turn brought on chronic migraine headaches. This also increased the very serious risk of having a major stroke, as she had already suffered at least four mini-strokes.

As you can imagine, my mother consequently became horribly depressed to the point where she required psychological counselling. At the outset, this debilitating condition has seriously affected her quality of life and that of my father as her carer who, incidentally, was diagnosed earlier last year with Parkinson's disease. My father told me with tears in his eyes several times that there have been times when she would cry in his arms saying she doesn't want to be here anymore due to the fire burning relentlessly inside her arm, hand and fingers. It has only been the love and support from her caring family that has kept her strong and helped her to try and live with it as best she can.

My mother has spent four years being shuffled around so many specialists, trying to manage her painful PHN condition by taking expensive heavy-duty prescription drugs such as OxyContin and Endone, both of which she is no doubt addicted to, plus Lyrica for four years, Prednisone for four years, the chemotherapy drug Methotrexate, and codeine, just to name a few. Further, there are medications she has taken to counteract the side effects caused by one or another medication. It is very important to understand that these hard-core prescription drugs are not designed for long-term use. They are only meant to be temporary, as the damaging effects on the body's organs, such as the liver, can be devastating.

Subsequently, my mother has sadly been advised by the medical experts that she has reached the end of the pharmaceutical road. There is nothing more they can do for her. Consequently, she is currently in St Vincent's Hospital, Brisbane, for two weeks, undergoing pain management therapy as we speak, with a view to preparing herself to wean off overprescribed pharmaceutical drugs she has taken for so many years, damaging her body, mind and spirit.

So the question arises again: where to from here? You guessed it, and again the results now speak for themselves. Against her better moral judgement, my mother started using medicinal cannabis tincture at night in January and her results have been miraculous. She had developed chronic sleep apnoea due to a side effect from taking the prescription drug Prednisone, which caused her to rapidly gain excessive weight—12 kilos. This weight gain, combined with the cocktail of other pharmaceutical drugs she was taking, caused her regularly to stop breathing many times in her sleep, sometimes for up to a minute at a time.

Data captured by her continuous positive airway pressure machine—or CPAP device, as it is commonly known—used to manage her sleep apnoea, confirmed that the several one-minute durations of time she stopped breathing have no doubt contributed to her experiencing at least four mini-strokes.

However, on a positive note, I am excited to share with you that from the exact day in January she started taking a few drops of hot medicinal cannabis tincture at night and also a few drops of cold medicinal cannabis tincture in the morning, her sleep apnoea has completely ceased, right up to her being admitted to hospital two weeks ago to undergo her pain management therapy. We have electronically recorded evidence of this, which the CPAP device logs for clinical reporting to her specialist.

In terms of the chronic pain, the burning sensation my mother normally experiences every day in her hand, ranked on a scale of one to 10, with 10 being she wants her arm amputated, typically hovered at around seven out of 10. However, after using the tincture it reduces to anything as low as three to five, which is a very promising result when considering this is only early days and also the cocktail of drugs would be working against the medicinal cannabis tincture.

Incidentally, my mother consulted with a number of her specialists about her intention to trial medicinal cannabis tincture, and none of them had any issue with her, apart from one comment that it is perhaps illegal in Queensland.

As previously mentioned, my dad was diagnosed with Parkinson's disease last year. He was prescribed two pharmaceutical drugs, Sifrol and Azilect. Apart from increased drowsiness after eight months of use, these had very little to no effect on his symptoms, which included stooping, memory loss, vagueness, headaches, uncontrolled drooling and dribbling, lethargy, and broken sleep, which was confirmed by his sleep study test, when he was diagnosed with moderate sleep apnoea.

At the outset my mother and all our family were sadly watching our family's role model slowly deteriorate, and all the neurologist could do was to increase the meds. But my mum and my family decided this was not good enough, and unbeknown to his neurologist we trialled him on a few drops of mum's medicinal cannabis tincture. Within days of dad taking a few drops of both the hot tincture under the tongue each night before bed and a number of drops of the cold tincture in the morning, the transformation in dad that we experienced was nothing short of miraculous. Within a week he stopped dribbling, he started cracking jokes with my mother as he used to do and he started singing again to her like he once did. He started to do so many small jobs around the home that my mum actually ran out of things for him to do.

Most amazingly, he started sleeping right through the night, not even waking once to use the bathroom, as he regularly did several times during each night. In fact, his CPAP device that he uses to manage his sleep apnoea showed that the apnoea had completely ceased from the day he started taking the tinctures in January this year, despite his sleep studies indicating a far greater apnoea problem. We also have electronically recorded evidence of this, which the device logs for clinical reporting. It is unbelievable, to say the least.

Dad's long-term friends have also commented on how well he is now, and the fact that he is now able to recall events and people's names from decades ago. He himself can feel this unbelievable transformation inside, and my mother often says to family and friends that she has the husband back that she married 51 years ago.

The first time we heard of the term "medicinal cannabis" was when my wife sustained a back injury in 2006 where she crushed the sciatic nerve at the L3, L4, L5 and S1 vertebrae so badly that for nearly six months she was unable to shower herself or use the toilet on her own. She could not drive a car and would sleep on the floor with a towel rolled up and placed under her lower spine.

She went through extensive counselling and was prescribed quadruple dosages of Tramadol to try and manage the pain. As this had little to no effect, her doctor, to our great surprise, encouraged her to source and use medicinal marijuana. However, due to our uneducated minds at the time, we did not consider this as an option.

As a matter of further interest, and like many other families, we have also witnessed firsthand the fallout caused by cancer. My wife's mother, a non-smoker and non-drinker, suffered horribly from toxic chemotherapy and targeted radiation to treat bowel cancer after having a significant portion of her bowel removed. However, sadly, all the pain and suffering she endured for so long was in vain, as the chemotherapy failed and the cancer spread to her brain, liver, lungs and kidneys. She continued to suffer with nausea and pain for as long as she could until her eventual passing. If only we had known about medicinal cannabis back then, it would have made her pain that much more bearable and her life so much more comfortable. It was inhumane to see a loved one suffer so horribly for so long. I am sure we all know others who have been down this path.

In closing I respectfully ask you: where do we go from here? Please, what would you and/or your family do if put in the same situation as ours? The two main biological instincts of every human being are survival and reproduction. In fact, these are the two main biological instincts in all living creatures and plants. Naturally, it will always be an instinctive trait of human beings to do whatever is necessary to stay alive and maintain quality of life, even when it means breaking an unjust law.

So, there are some questions that need to be addressed here. Firstly, how and why should it be allowed to happen that someone can become a criminal simply because they want to live? They are not pushing or selling a drug but are simply using a medicinal form of a plant or vegetable to improve their own health or way of life. Secondly, why is using medicinal cannabis an illegal criminal act to relieve chronic pain when on the other hand it is legal to take and become addicted to opioids to relieve chronic pain, just like my mum is?

Thirdly, why is using medicinal cannabis a criminal act when someone needs to escape the suffering and ravages of chemotherapy, just like Dan Haslam did? Fourthly, why is using medical cannabis a criminal act when a child suffering hundreds of seizures a day, causing irreversible brain damage, shows a dramatic improvement immediately after using medicinal cannabis tincture, just like so many children are living proof of doing, as documented in any number of online videos?

Fifthly, why do I, or any other Australians for that matter, have to sell up everything and leave this beautiful country we were born in to move to the likes of Colorado in the USA just so that we can legally access medicinal cannabis? The economy and real estate there are booming while crime is declining, all because of the legalisation of cannabis.

Finally, just reiterating my original question, what does one do when they are informed by the medical experts that they have sadly reached the end of the pharmaceutical road? The bottom line is: access to medicinal cannabis is crucial. The evidence is overwhelming, and the unjust laws must change to reflect the will and need of the people. I am pleading with you to please do the moral thing. Thank you for your time.

THE CHAIR: Thank you for that statement. We will now get committee members to ask some questions of you. I will start first. Do you think, Grant and Kathy, that people growing cannabis themselves and self-medicating is the practical answer, or do you think a medical-grade cannabis system available on prescription from a dispensary is the best way to go?

Mr Beale: This is something that we researched a lot. I believe there is room for both. There will be people who are not in a position to be able to grow medicinal cannabis themselves. For example, for my parents, it would be far more practical to be able to go to a dispensary and pick it up themselves. However, I know of the benefits of growing it themselves with respect to convenience, quality and a number of other factors. So I think there is a place for both processes. My wife is sitting beside me. We are sharing one phone, and she cannot actually hear your question.

THE CHAIR: Would you like to put her on, and I can ask her the same question.

Mr Beale: Okay. Thank you.

THE CHAIR: Kathy, it is Chris Bourke here, the chair of the committee. I will ask you a question, if you do not mind. The question I asked Grant, which he just answered, was: do you think people growing the cannabis themselves and self-medicating is the practical answer to this issue, or would you see a medical-grade cannabis system available on prescription from a dispensary as the best way to proceed?

Mrs Beale: I think both would work well. There are already people growing their own. We have been to a lot of workshops and learnt a lot from that, and from online. I believe that both would work well.

THE CHAIR: Kathy, one question that has been put is that there is a greater risk of diversion for recreational use from home-grown cannabis. What would you say to that concern?

Mrs Beale: Recreational? I know of some people that use recreationally for PTSD and other medical disorders that they have. It would probably come back to going to doctors and specialists and working with the medical profession to work out what they should do. I am not so much for recreational myself.

THE CHAIR: Grant, I will ask you the same question that I asked Kathy. There are some concerns that allowing a home-grown regime may lead to diversion for recreational use. What do you think about that concern?

Mr Beale: Recreational use has certainly been a hot topic. Realistically, at the end of the day, no matter what it is, it all gets back to appropriate education. With respect to recreational use, alcohol and illicit drugs are out there; it cannot be denied. Cannabis is a substance that is safer than table sugar. With the right education, I believe it can work. I really do not see it being a major issue.

THE CHAIR: Thank you, Grant. I will ask Mr Wall to ask a question.

MR WALL: Thank you, chair, and thank you, Grant, for joining us today. You mentioned that you did a fair amount of research or analysis of the scientific evidence that is out there. Did you come across any evidence of side effects that the long-term use of cannabis may have or any correlation to a need for or a dependence on using it after an extended period of time?

Mr Beale: That is a very good question. I am a computer programmer by trade, a database engineer. I have learnt a lot of something outside my field. I have read a lot of peer reviews and a lot of scientific journals. I have not really come across anything that shows any proof of long-term issues. The only thing that I have seen is that with medical cannabis there is not one strain that suits all. People I have consulted with in the USA have talked about dosage requirements. There are different strains and there are a lot of factors that impact on the type of cannabis to attend to the needs of the person. That is something that, once again, gets back to education.

MR WALL: You mentioned that you have sourced a tincture.

Mr Beale: Yes.

MR WALL: For those on the committee and anyone reviewing this hearing, what actually is a "tincture"?

Mr Beale: A tincture basically is a liquid that cannabis oil is produced in. A tincture is the carrier. There are various types of tinctures. There are olive oil based tinctures, coconut oil based tinctures and hemp seed oil based tinctures. It is something that allows the cannabis oil to be dosed. It usually comes in a bottle with an eye dropper so you can administer so many drops.

MR WALL: Is that something that you have taken to producing yourself for your family, or do you have a supplier?

Mr Beale: No. We have produced absolutely nothing. We have sourced this from reliable suppliers and we have recently, probably in the last six months, been educating ourselves on ways to produce it in the hope that we can eventually make it ourselves.

MR WALL: Obviously, regarding the cost and efficacy of any medicinal cannabis scheme as part of it, what sort of price are you paying for the tincture or is it an in-kind gift?

Mr Beale: In some cases it has been a gift to trial to see if there were benefits to my parents' ailments. But I have seen tincture prices, depending on the size of the bottles that they come in, from $50 for 25 millilitres to $50 for 50 millilitres, depending on the strain and the strength. But keep in mind that, when it is taken, it is only used in drop form, so a small bottle goes a long way.

THE CHAIR: I will turn to Ms Fitzharris now, who will have a question for you.

MS FITZHARRIS: Thanks to you both for sharing what is a powerful story, particularly with regard to your mum.

There are two sets of questions. One is around the decision-making that your family had to go through on the supply side. I am guessing it was a fairly significant decision to come to, to source medicinal cannabis. Can you talk us through a little bit about what you had to do to actually find it and what sorts of thoughts you had as a family about what implications there could be for you sourcing it on behalf of your mum and for your mum taking it herself?

Mr Beale: Certainly. That is a very good question. I must say it was a very, very difficult process. Because of the sensitivities surrounding cannabis in terms of legalities and whatnot, it is not a substance you can go and ask people for. However, obviously the herb itself is available anywhere. I could go down the street and be back in 10 minutes from people I know that have the herb, but it is not about the herb so much as it is about the oil. The oil requires a process to produce.

As for sourcing it and for convincing my parents to take it, that was a very, very hard process to start with. My parents, when I first mentioned to them the medicinal values of cannabis and what I had read, wanted to know nothing about it. I am not a religious person, but they are very, very religious people, very moral people. They have a great standing in the community, have done a lot for the community, and they were very hesitant, very sceptical, not knowing anything about it. However, I chipped away for a long, long time and eventually they came around.

I attended a number of forums, public forums, a number of workshops around New South Wales and up here in Brisbane to learn. I actually even took my parents along to one to listen—not just to listen to the people talking about the benefits of cannabis but to actually listen to sufferers, people who had already had great results. I needed to show them evidence. And not just anyone—I am talking about young children who

are suffering seizures, and the parents of these children. As I said to my mum and dad, I looked at these children that are having seizures and it is a no-brainer: give the child the medical cannabis and they live and do not suffer any brain damage or do not give it to them and they potentially die or suffer brain damage. It is compelling evidence to see the miraculous change in these people. Consequently, that had a big impact on my parents.

I have a family; I have brothers and sisters. It gets back to education. You mention the term "cannabis" or "marijuana", the alarm bells go straight up. It is how people have been brought up. The stigma attached to that name is just so powerful. Once again, slowly chipping and chipping away, we have all their support. So it was a hard journey to start with. I have even actually said to my parents, "What would happen if you had a knock on the door?" My mum's and dad's response was, "We'd be more concerned about losing our medicine than we would be fronting up to a magistrate." That is how much they have turned around. If it was legalised—my mum is a green thumb; she has won gardening contests—she said she would actually even have a go at growing the herb herself.

MS FITZHARRIS: You mentioned initially for Kathy that there was a recommendation from a doctor to possibly try it, which I guess led you down this path, but for your mum the doctors got to the point with powerful prescription medication where they said, "We've reached the end; there's nothing more we can do for you." Did you discuss with the doctors what medical cannabis could do or did you have any discussion with any of your mum's doctors around the use of medical cannabis?

Mr Beale: I have not, but my mum certainly asked a number of her doctors. I actually gave my mother and father a question to ask. I said, "When you see the doctor, I would just like you to ask them, if you could, a fundamental question for me: what do they understand about the endocannabinoid system, ECS? That is all I want them to ask, and just see what their response is." This is an important part of understanding how cannabis works in the human body. There were mixed results. Doctors did not have any issues. There were a lot of doctors that did not know about the endocannabinoid system. Some had heard of it but knew very little. So it was an education thing. But the doctors did not have any issues with my parents trying it.

With respect to Kathy's doctor, we were stunned, back at the time, that a professional doctor would suggest using medicinal cannabis, as it is an illegal substance. When we left the surgery at the time I remember saying to her, "We can't just go down to the chemist and buy it. It's good and well to say that, but where do you get it and how do you use it?" It is education. We had no idea. But the lady doctor at the time said she had patients who had used it with great success.

MS FITZHARRIS: Thank you, Grant.

THE CHAIR: Grant, I'll hand over to Ms Lawder to ask a question as well.

MS LAWDER: For your mother, has using the medicinal cannabis, or cannabis for medicinal purposes, reduced her use of prescription or over-the-counter drugs as well?

Mr Beale: That is a good question, and that is something that we are working towards

right now. She is in the St Vincent's Hospital, and has been for the past two weeks, undergoing this pain management therapy with a view to weaning her off the prescription drugs. Last month it took her about four weeks—I think it was about three or four weeks—to wean off Lyrica, with horrible side effects. Her muscles stiffened up, she could not sleep at night and she had creepy crawlies on her skin. Anyway, we researched it and spoke to a few people, and one of the other drugs she was taking with it at the time, Panadol, was causing a reaction. Anyway, she finally managed to wean herself off it. She started feeling so much better—so, so much better. Because she was feeling so good, her goal was to wean herself off all pharmaceutical drugs to try and manage this pain.

They have taken the next step now to see if they can go into this pain management therapy program to actually see how she can manage the pain slowly as she weans herself off these drugs. That is the goal for her. If this can happen, it will be wonderful. As I have said, I have read up about drugs like OxyContin, Endone and Lyrica. These drugs, really, impacting for four years on your body, it is big time. I said to my mum—she is 71; hopefully she will live another 20-plus years—"You can't go on taking those sorts of drugs for the rest of your life and then have to take more medication to counteract the effects of those drugs." The science of the medicinal cannabis was so overwhelming that we decided to go down this path.

MS LAWDER: I presume that while she is in hospital she is potentially not using the cannabis.

Mr Beale: Absolutely correct, yes. She obviously cannot do that in there. They had it stopped.

THE CHAIR: Thank you, Grant and Kathy, for your submission and your testimony today and answering our questions; it was very much appreciated. There will be an opportunity to get a copy of the transcript next week from the secretary, Nicola. Thank you for joining us, and we will say goodbye now.

The committee adjourned at 11.34 am.