

Submission to the Victorian Law Reform Commission

MEDICINAL CANNABIS REFERENCE

Number	49
Name	Shirley Humphris
Date	26 March 2015



Cambrie Humphris and her father Robert

My 2-½ year old granddaughter, Cambrie, has intractable epilepsy. This means no pharmaceuticals work. She has been trialed with over 12 antiepileptics all with frightening side effects and some with unknown long-term risks for children. She is now on SAS drugs (i.e. non approved trial drugs).

I am including a link to newspaper article that may give some insight into our family situation. Nothing has changed, in fact Cambrie's many daily seizures are worse, some lasting 20 or 25 minutes. She is considered palliative. Her father, a paramedic, can only work 2 days a week. Cambrie has an older sister age 7.

The journalist focused on trials, as they were newsworthy prior to the election, but this will be too late for us, as trials through TGA require scientific evidence. Clinical trials, rightly, take years of double blind studies. Children, like Cambrie will die, or be further brain damaged waiting to get onto trials and she may not even be accepted onto the trial, as the cause of her condition is unknown. Her genetics study, that took 18 months, revealed no known gene and she will now undergo full genome analysis that will take 12 months plus.

We should not have to go to the street to find some hope for Cambrie. We need a supply that is clean and grown under controlled conditions (street cannabis can be heavily laced with pesticide). I, and all of my 4 adult children and their spouses, do not drink alcohol or smoke as we all attend a church with this value. Imagine if we had to resort to growing an illicit plant. We would then have to figure out what to do with it. We are most interested in an oil or tincture.

I am not opposed to legal growing of a small supply of the plant if a manufactured supply becomes too expensive to those who need it but a medicine is more useful to us and we could pay. State controlled supply may keep prices reasonable and home growing unnecessary.

I hate to specify illnesses for fear of leaving some out, but in my immediate family we also have Lupus (my daughter), Parkinson's (her father in law) severe bone cancer (my father), early onset Alzheimer's (Cambrie's grandfather). None of these sufferers have found effective relief, without severe side effects, from existing pharmaceuticals. Lupus is not mentioned on your list but is an insidious autoimmune disease that can affect several organs (including renal failure, heart complications and blood clots) as well as giving, fatigue and inflammatory arthritis like pain. Current medications are limited and the most effective is cortisone but this has had to be scaled back due to side effects and is not a long-term option for a young woman. There has been some limited references to cannabis helping lupus sufferers and is of possible benefit due to the anti inflammatory benefits of cannabis. Lupus may not fit your criteria but my daughter's condition is likely to drive her to an illicit supply despite being a practicing Christian.

In summary we do not really know, for sure, the exact risk / benefits because of the historical legal problem with cannabis. However those willing to take the risk should be given the right over their body. Pharmaceuticals are presented in this way and the patient assesses their risk / benefit with their doctor.

Incidentally my 86-year-old father has a draw full (he forgets what he has and fills new scripts) of endone, targin, codeine, fentanyl patches and morphine ampoules. I have a similar stash at my house because he forgets his when he visits. They were very, very easy to obtain. Please remember illicit and prescription drugs are out there anyway so fear of the illicit use of cannabis should not be the cause of suffering of the very ill.

The far-reaching promise of this medicine is worthy of government support and expenditure. It may well prove cost saving considering the high costs of pharmaceuticals as well as disability support, hospital admissions and workforce participation etc.

The overriding legal question is **how far should we cause the seriously ill to suffer (even maybe giving the death sentence) to protect those who choose to abuse their bodies?** This issue must not be filed as too hard yet again.

Please open this link

<http://www.geelongadvertiser.com.au/news/geelong/medical-cannabis-trial-a-final-hope-for-cambrie-humphris-and-her-parents/story-fnjuhovy-1227041463166>

Questions

1. Considerations to determine exceptional circumstances.

a) the circumstances of the patient

2. For what conditions...

There are very many conditions of promising benefit, but potential risk / benefit is the only criteria that should be used or cannabis is limited to clinical trial evidence if "sufficient knowledge" criteria is used.

In short people should be given the option to try cannabis as an informed choice. The benefit could be substantial with the risk less than that of current meds that have known risks.

There is a case for the harms of cannabis to be taken into consideration, however many are living with significant and devastating side effects of other drugs that they are prescribed now.

3. What special considerations....

a) Palliative care, the illness is harming (e.g. epilepsy, cancer) or where alternative medication side effects are harmful or debilitating.

b) As above

4. eligibility

d) evidence that all reasonable (*but not exhaustive or time wasting*) conventional treatments have been tried and failed - *or have unacceptable side effects*.

5.special cases..

As above should cover this.

6. TGA Act Narcotics Act ...

Unable to comment

7. Regulatory objectives sufficient..

Unable to comment

8. .. defense to prosecution ...

Yes or police would be left to turn a blind eye. They can already do this (called discretion or even "not noticing") but this is not a solution.

9. ...cultivation ..

Presumably similar to the poppy industry. It must be possible to grow and manufacture a secure supply. A plant that is not heated (as in an oil or tincture) is not psychoactive so illicit use of this product would be less likely. CBD only would be useless recreationally so could be supplied differently with less security of growing and distribution.

Some illnesses respond to THC or a combination of both however, and therefore this product is needed.

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10. See 9

11. regulation and distribution ...

This would probably be best achieved through poison regulation not TGA, if TGA can only operate with clinical trial evidence. For the future, federal legislation needs to change soon to avoid the US situation. Hopefully the states will influence this.

Immediate reclassification of low THC, high CBD plant is imperative as this restriction of a non psychoactive product makes no sense.

12. responsibilities of health practitioners ...

A doctor maybe would not exactly prescribe cannabis in the usual way (doctors may fear potential litigation for "prescribing" an untested product with unknown dosage) but rather certify the illness or symptoms. It would then be legal to have the discussion with the doctor re risks and benefits without fear of being informed on. Importantly the doctor would be able to run tests to monitor the effect cannabis may be having on existing meds (it is known some the concentration of some epilepsy meds are affected by cannabis). In short, it would all be above board and some help would be available. A present there are only whispers from a small community willing to share their experience.

Although tight controls and responsibilities would seem intuitive these seems to be lacking with other prescription medicines that have far more damaging implications in the wrong hands.

13. b) authority to assess ...

Specialist primarily but may need to authorise others for remote patients.

14... guidelines for health practitioners..

Legislation should be able to track over use (and illicit distribution) via a register. Otherwise advice should come from within their profession rather than legislation

15...age or capacity

medical specialist opinion should advise this not politicians. Sick children are given risky medications in similar circumstances.

16. tincture, oils, although smoking is a health hazard and heating psychotropic some illnesses (e.g. neuropathic pain) may need the fast relief of smoking / vaporizing. Also future harms are not an issue for those with terminal illnesses.

Consumables that look like lollies/chocolates are a risk to children and should not be available.

17. with close cooperation and funding to research institutions. NB this natural product does not attract funding so this would need government support. Expense should be viewed in the light of potential cost saving in other medical fields e.g disability support, hospital admissions, parent workforce participation etc.

Shirley Humphris