Submission to Select Committee into Cannabis and Hemp

Legislative Council of Western Australia

Terms of Reference:

1. the current barriers to pharmaceutical nutraceutical use of cannabinoid products;

2. medicinal cannabis, its prescription, availability and affordability;

I am the carer for my Mother in Law (MIL), who at 78 years old suffers from Parkinson's Disease (PD) and associated Lewy Body Dementia (LBD). She has been treated with traditional PD medication (approx. 6 years) and also with tetrahydrocannabinol 10mg and cannabidiol 10mg medication (approx. 5 years) at a dose of 0.6ml 3 times per day.

The side effects of traditional PD medications are well documented and publicised. They are debilitating and awful, especially for an elderly patient trying to obtain the best value from their remaining life. These drugs leave you feeling unwell, groggy and can trigger dyskinesia, uncomfortable involuntary movements which are different to the tremor suffer by Parkinson's Disease.

After much worldwide research, we chose to obtain THC:CBD oil to enhance the traditional treatment of her disease and to obtain the oil legally through a Doctor's prescription. Despite asking her regular General Practitioner (GP) and other GPs in our small town, no one would or could prescribe the oil. We eventually found a GP sympathetic to our case in Dunsborough, travelled there (a 2-hour drive) and subsequently obtained the prescription and oil from the Dunsborough Pharmacy.

After treatment with the oil, the improvement in MIL was immediate and the benefits continue to this day. I have listed them below:

- Dramatic and immediate reduction in tremor and "freezing" while walking, associated with PD,
- Immediate improvement in appetite and a renewed interest in food and drink, plus a reversal of steady weight loss – malnutrition and weight loss are common in the elderly with PD and LBD due to reduced appetite and lack of interest in food,
- Immediate cessation of anxiety, paranoia and the desire to run away from home, associated with LBD, thus reducing falls risk and increasing happiness and comfort,
- Immediate cessation of sundowning and night terrors associated with LBD, also reducing falls risk and increasing happiness and comfort.

My points for the committee I have listed below for ease of consideration:

1. **Barriers**: The barriers are many…
    a. **The archaic and old-fashioned attitudes of the medical profession and the Health System:** This is probably the greatest barrier we have come up against! MIL was admitted for a month long hospital stay recently due to mismanagement of her medication (the PD meds, not the THC:CBD oil) by her elderly husband. I have since taken control of all her medications and I administer them myself. On admittance to hospital, we were told we had to supply an unopened bottle of oil $197.50 value so that the hospital nurses could dispense the oil themselves. I believe having to supply a drug is <u>not</u> the case for any other prescription drug, certainly not in my experience. We suffered a lot of judgement and push back from certain health professionals, including one RN who just <u>did not</u> administer the required oil dose. Within the Manjimup Shire Health and Community Care staff (HACC), who manage MIL's My Aged Care L4 Home package, we have had a Registered Nurse (RN) snooping around MIL's home as she was under the assumption that we procured the oil illegally and I guess she was trying to get us into trouble? Who knows, this is a small town and I have not pursued the matter as I do not want to compromise the level of care that MIL receives.
    MIL's Gerontologist totally dismissed the benefits of the oil to MIL and refused to contemplate the improvements she had experienced due to taking the THC:CBD oil. Just the appetite improvement and reversal of the weight loss MIL had experienced in my opinion has saved many, many health dollars, as she is not as high a falls risk as she would be if underweight and frail. Definitely her risk of broken bones is way less than someone malnourished and underweight. MIL unfortunately developed pressure sores on both heels whilst in hospital. The fact that she is able and willing to consume good nutrition has meant that these very serious hospital acquired injuries are healing, with one heel completely healed and the other heel healing well. Pressure sores can be fatal in elderly, frail and malnourished patients. Despite her advanced diseases, MIL has not had a repeat admission to hospital and this stay has been the only admission in the 6 years since her diagnoses. This in itself is a very rare occurrence and has saved many thousands of dollars and huge amounts of saved resources to WACHS.

    b. **The fact that THC:CBD is a Schedule 8 Drug:** This scheduling is ridiculous and creates barriers in who can administer the THC:CBD oil. Only a Doctor or RN can administer a Schedule 8 drug and Medication Competent Support Workers <u>cannot</u> legally administer these drugs.

MIL goes to day respite twice a week and on one of those days the HACC RN is not at work. To have the HACC RN administer the dose, I have to take our bottle of oil to the local Pharmacy and pay for them to draw up and label a dose so the HACC RN can legally administer it! We then have to pay the HACC RN through the L4 package 0.25 hours of time to administer the dose. As the L4 package cannot possibly cover the services, equipment and continence supplies we need to properly care for MIL at home, we have chosen NOT to have the HACC RN administer the oil. We have had to modify her dose (half dose before she goes and half dose when she returns) or the alternative is to go to the respite centre ourselves to administer the oil. The whole point of respite is to have a break from carer duties, so we chose to modify the dose. The Support Workers at the respite centre all agree that the lack of a full lunchtime dose definitely impacts MIL's comfort and her behaviour, mobility and cognitive ability is way better when she is able to have the full lunchtime dose as prescribed. It is ludicrous to have this oil in the same class as opioid drugs as there is just not the same risks of dependency and/or misuse of the drug. Not only does this scheduling cause issues at respite it also caused issues whilst MIL was a patient in hospital. Why should MIL, who is so dear to us, suffer because of the bureaucratic nonsense around the scheduling of this drug? It also prevents us from having any in-home respite, because we would need to pay RN's to be carers so that we could keep within the law and scope of practice of their qualifications in regards to medication administration. <u>We, the family, have not had a weekend away or even a night off in years.</u>

2. **Prescription, availability and affordability**
   a. **Prescription:** Due to the limited number of GPs willing or able to prescribe THC:CBD products, many patients have difficulty finding a GP who can provide the service they require and have to travel a long way to attend appointments. It is very disruptive to families to have to do this. The GP we currently see for prescriptions charges $150 for these appointments and due to him being unable to prescribe more that 100ml at a time, we require these appointments every second month. The cost and time taken to get a prescription is prohibitive. We do use telehealth consultations now as MIL is unable to travel, but the costs for the appointment remains the same.
   b. **Availability:** CBD:THC oil is not generally stocked by pharmacies and we have to be careful that we overlap prescriptions as it takes 3 – 4 days for the Pharmacy to get our prescription into stock. When MIL was admitted to hospital in Manjimup for a month, we had to supply the oil to the hospital Pharmacy, which I believe is <u>not</u> the case for any other prescription drug, certainly not in my experience.

c. **Affordability:** Currently we pay $395 per 100ml for THC:CBD oil. This works out to be $2.37 per dose, $7.11 per day, $49.77 per week or $2,588.04 per year. If you add the $900 per year cost for prescription issue, that is a total cost of $3488.04 per annum. This does not include any travelling to appointments (which we now do not do) This is not affordable for the very people that need the oil the most. MIL is a fully self-funded retiree, having been an intergenerational farmer and while she doesn't have a lot of cash, the value of the farming land assets owned prevents her accessing any Services Australia (Centrelink) assistance in the way of a pension.

I hope by telling my story and that of MIL, I am able to influence some changes to the attitudes and legislative framework that is set around the prescription and administration of this drug. The benefits of this drug for MIL have far outweighed any traditional treatment that has been offered and gives MIL some quality of life whilst suffering this debilitating, dreadful and terminal disease. The fact that THC:CBD oil is deliberately withheld (in some cases) and not accessible or affordable to people that would/could benefit from it is truly horrifying. Every human being suffering from debilitating and terminal illness deserves the opportunity to be treated with drugs that add to their comfort and wellbeing – whether that be a traditional drug treatment or a newer treatment such as THC:CBD oil. The fear and misinformation inferred by our medical fraternity to patients and families in regards to this treatment is every bit as horrifying and tragic as die-hard anti vaxxers in my opinion. The fact that legally obtained oil is so difficult to source and so expensive in comparison to illegally sourced oil is unbelievable!

I am happy to discuss further and am available on the phone number below.

Author: Jennifer Elms