

27<sup>th</sup> December, 2014

An open letter to Tasmania Police, media, politicians and the public,

My youngest brother, Tim has been using medical cannabis for the past two months with significant benefit. He acquired a brain injury at 5 months of age (bacterial meningitis infection) then began having epileptic seizures (as a result of the brain injury) 11 months later (he is now 28 years old). Tim had been prescribed a range of anti-convulsant medications since he was diagnosed with epilepsy through until he was 18 years of age – at that point, my parents were advised (by doctors and specialists) that he should not try any further anti-convulsant medications, as he had developed severe reactions to all of them. It was determined that anti-convulsant medications would not work for him, and in fact were unsuitable for him.

My parents have tried a range of natural therapies, with some benefit to Tim's health and wellbeing (gluten-reduced diet, magnesium supplements, massage, homeopathic drops, etc). However, it seems much of his seizure activity and challenging behaviours also arise from ongoing infections (he often suffers ear infections, throat infections, digestive problems, etc). We noticed about two years ago that every time Tim was prescribed antibiotics, he would have less/no complex partial seizures (but he still continues to have the severe tonic-clonic seizures). We asked our GP to prescribe Tim a lengthy dose of antibiotics around 6 months ago (which he did, but after several months, he said the long-term side effects were too risky) – Tim gained significant health and wellbeing outcomes during this time, along with better quality of life.

Around two months ago, due to the generosity of friends and acquaintances, we were able to acquire a sample of cold processed (THC has not been activated) medical cannabis oil to try. Tim received even better health and wellbeing outcomes than he had on antibiotics, and gained other benefits such as increased muscle tone (he often struggles to walk or even hold his own body in a sitting position). We believe the benefits arise from a combination of both the anti-convulsant properties as well as the antimicrobial properties of cannabis. He has had no side-effects from the medical cannabis in the two months he has been using it. However, our supply is just about to run out.

A brief summary of what medical cannabis means to Tim's quality of life:

- It means he can feed himself some days (and can even hold a bowl in one hand and a spoon in another).
- It means he can sometimes indicate whether he wants or does not want something – such as food, a drink, a certain DVD.
- It means he can walk without assistance some days, and even get in/out of a bath with little help at times. He can also sit up better (due to better muscle tone, as well as better coordination).
- It means he can do jigsaw puzzles, drawings, etc on a good day to stimulate his brain and keep himself occupied, due to having almost no complex partial seizures
- It means he can learn to use some simple brain development activities on his ipad and watch youtube clips.
- It means he can watch a DVD right through, and for the first time in his life understand the story line (as he is no longer having continual complex partial seizures that interrupt his life

completely – he used to watch a DVD dozens of times, sometimes 5-6 times in one day in an attempt to try to understand the story line).

- It means he usually wears clothes, rather than wandering around completely naked.
- It means on some days his challenging behaviours can be somewhat managed through rationally talking with him about the consequences of his behaviours.
- It means he can sometimes laugh and understand a joke or something funny.
- It means he no longer has serious cluster seizures which result in him being hospitalised for days (his cluster seizures usually now are only 4-6 in 24 hours, rather than up to 20 or so).
- It means that although he still has tonic clonic seizures, he recovers much quicker/better.
- It means he is much more aware of other people and other's needs.
- It means he can understand conversation so much better.

These are significant health and wellbeing outcomes for a young man who has never really experienced quality of life before. If we could continue to access medical cannabis, I am confident he will continue to gain significant improvements and quality of life. Unfortunately, it seems the state and federal governments are cruelly uninterested in assisting the most vulnerable and suffering members of our community to live a life worth living.

We were given around \$1000 of medical cannabis oil (around 6-8 weeks supply) – if it were not for the generosity of friends, there is no way we could afford this (Tim is on a disability pension; my parents are on carers pensions and have no capacity to work as they both care for Tim 24 hours a day/7 days a week; and I am a low income earner. Due to the impossibly high costs, we have no choice but to grow our own cannabis.

Whilst there have been statements made by politicians that those who have made submissions to the Legislative Council Select Committee on Medical Cannabis will not be prosecuted for their use of medical cannabis, I would like to know more details on this, including where I, my family and my friends legally stand in regard to:

- Growing cannabis plants?
- Sourcing cannabis from other growers (which I have done to acquire the trial for Tim)?
- Transporting cannabis to processors (I have travelled with 3 ounces of cannabis in my car to take the raw material to a processor)?
- Giving cannabis oil to a disabled person with a brain injury and epilepsy who is non-communicative?
- Asking a processor to cold extract/process the cannabis and create cannabis oil?
- Transporting \$1000 worth of cannabis oil in my car and storing it in my home?
- Sourcing seeds to grow cannabis?

I and my parents are more than willing to discuss this further. We would also be happy to introduce Tim to anyone who is interested in meeting him and gaining some understanding about his disability and life.

Yours Sincerely,

Hannah Rubenach