

Thank you for the opportunity to speak to our experience with medicinal cannabis.

I am mother to an adult son who suffers from refractory epilepsy and an acquired brain injury.

He was diagnosed after suffering from suspected Acute Viral Encephalitis at age six.

He is now twenty four years old.

He has tried every suitable prescribed medication for seizure control. He has the Vagal Nerve Stimulator which was implanted when he was eleven years old – which also failed to control his seizures.

He is not a brain surgery candidate because he has too many seizure foci in every lobe of his brain.

We have been using medicinal cannabis to alleviate his post encephalitis symptoms and seizures since 2014.

Initially our medicine came from suppliers, both compassionate and from those who sold the medicine to us.

This supply was not consistent so we made the decision to grow his medicine.

We understand this is a great risk.

However, the personal risk to us by growing is nowhere near as great as the risk to losing our son to his next seizure.

Jeremy is at extremely high risk of SUDEP, sudden unexplained death in epilepsy. His specialists have warned us of this fact year after year. All while prescribing medications which not only failed to control his seizures but caused him significant side effects;

Allergic reaction.

Weight gain, he gained 26 kilograms in the first six months post diagnosis.

Insomnia, initially they added a benzodiazepine, Nitrazepam to counter this side effect. He has suffered severe insomnia for 16 years from the anti-epileptic medication Lamictal. He currently still takes this medication.

Cognitive delays- loss of already limited verbal skills when we tried Topamax.

Gum disease.

Weight loss, to the point where his Epileptologist reported a serious concern.

Toxicity – Jeremy was enduring drug induced toxic episodes at least five times a week. Around 15 minutes after medications were administered Jeremy would become ataxic, not able to stand, suffered from blurred vision and vomiting. Jeremy appeared “drunk”. These episodes lasted for around an hour.

Respiratory distress. Jeremy has been prescribed Midazolam for prolonged seizures (over five minutes) and for cluster seizures (minimal recovery to consciousness between seizures) Ideally according to Midazolam safety and warnings, it should not be administered outside a hospital setting, and only with personnel available able to maintain airway. Every time we administer Midazolam we must do so very slowly, one drop every ten seconds. The first time we administered Midazolam at home, Jeremy suffered a serious cyanotic event. Thankfully we are trained in oxygen therapy and have oxygen at home.

Drug induced psychosis. Jeremy has suffered this side effect most prominently from two of the medications he has used. Keppra and more recently, Vimpat. Earlier this year when we increased Vimpat to the target dose prescribed by his neurologist Jeremy's behaviours spiralled out of control. We were forced to keep him at home as it was too unsafe for him to enjoy his usual daily activities with his support workers. We had to put all loose objects away as they became objects for him to use to punish people. We could not go near him, brush his teeth, shower him, dress him or even tuck him into bed. He hospitalised one of his support workers who subsequently had to have several weeks off work from the injury he caused her. He tore apart the waiting room at the Mersey when we attended a pre-admission clinic for dental work, throwing chairs and magazines around the room. He tried on many occasions to exit a moving vehicle, undoing his seatbelt and trying to get out of the car. He had kicked from the back seat at the driver, and knocked the car out of gear.

Our decision to try cannabis evolved from advice from his Neurologist mid-2014 to use sedatives.

We did not want to sedate our son with more chemicals.

A chemical straight jacket is no life for anyone.

We were advised by many, including our State Health Minister to discuss our desire to trial cannabis with our Specialists. Our specialists' hands are tied by legislation in this Country. Our GP is very supportive but he cannot advise either.

Our choice to use cannabis has also proved to be disrupting Jeremy's life further.

He cannot go to hospital; his support workers cannot administer his medicine. He cannot carry his medicine in public.

We know it works but he is restricted in every way when it comes to his cannabis regime.

Cannabis must be rescheduled. Cannabis does have medicinal value; this has been proven through study after study and in our own personal experience.

I fail to see how our Country cannot look to the experts such as in Israel who have been studying cannabis for decades and who are offering patients a successful cannabis therapy program.

Quality of life came from medicinal cannabis.

We grow his medicine as we search for the best cultivars for his needs.

I understand the need for regulated medical grade cannabis, I appreciate that many families wish to be able to access this legitimately.

Cannabis therapy is by far the most benign treatment we have ever used for Jeremy. He has suffered no unwanted side effects from cannabis and indeed; he is the healthiest he has ever been.

I am more than happy to provide more information should it be required.

Thank you again,

Lyn Cleaver