

I am a Neurologic trained and Registered Music Therapist (NMT, RMT). I work with children with disabilities, many of them with severe epilepsy. Using music based techniques to meet non-musical goals (speech/communication, motor skills, social/emotional skills, cognition etc) for children with disabilities is extremely beneficial and results can be seen sometimes in just one session and across several sessions. The children who experience severe epilepsy (uncontrolled seizures) have unfortunately very inconsistent results. A major seizure can mean a change in cognitive functioning and loss of skills. Side effects of heavy medication can also cause a negative change in cognitive and behavioural functioning which impacts heavily on the child's quality of life. These children will often have to go through several medication changes as their body develops and no longer responds to the dosage or medication type. This again impacts on their therapy progress. It can be very stressful and disheartening for the parents to see their child lose skills that they had worked so hard to achieve (and spent many therapy \$\$ on!). At the same time, these parents are often just thankful that their child lived to see another day – knowing that a seizure could kill them at any time.

On the other hand, I hear stories of children with severe epilepsy whose parents have access to medical cannabis oil. These children have less or no seizures after taking the oil and are able to regain functioning lost through brain damage from seizures and heavy medication. They can build their skills back again, regain quality of life and reach their full potential. The parents are less stressed, less consumed by their child's condition and can also regain quality of life.

In late 2004 my best friend who was a healthy young 22yr old male had a seizure. This seizure did not stop but thankfully I was present at the time and the ambulance was called. My friend, who had never had a seizure in his life, went into status epilepticus. In the days following, he did not respond to medications to stop his seizures and was put into a medically induced coma. He remained in this state for over 5 weeks. Each time doctors reduced the drugs to bring him back to a conscious state he went back into status. Finally, when he came out of the coma he was diagnosed with epilepsy and faced another several weeks/months in hospital rehab to regain lost skills. The next 18months were a daily struggle of constant seizures, medication changes, awful side effects and the emotional management of his new life (forced to move back home to parents as he needed constant supervision). In March 2006 he had one final seizure that killed him. The medications he was on had not worked.

Over the last 6months I have heard and started reading up on medical cannabis for the treatment of severe epilepsy. I certainly have a lot more to learn but the fact that it is legal (with sufficient research to back this decision) in several other countries leads me to question - why it is not legal here and able to be accessed by families such as those that I work with?

It saddens me to think that there is a possibility that my friend's death could have been prevented had there been knowledge of, and access to, medical cannabis as a treatment option (particularly after nothing else had worked). I hope that other individuals can be saved if a new law is passed. Please listen to these families.