

Six-year-old Caledon girl seizure-free thanks to medical cannabis

Changed the way Neurology Centre of Toronto's medical director views medicine

By Rob Paul

Right around her second birthday, Quinn, from Caledon, began experiencing debilitating seizures. Now, six years old, she has been seizure-free for over a year after being treated with medical cannabis.

Approximately four years ago, Quinn and her mother, Carrie, were referred to Dr. Evan Cole Lewis, Medical Director, Neurology Centre of Toronto and Chief Medical Advisor, JMCC Group, a specialist in paediatric and adult epilepsy.

Quinn was diagnosed with epilepsy by Dr. Lewis and prescribed a standard anti-seizure drug.

During Quinn's first year of treatment, Dr. Lewis tried several standard medications, none of which stopped Quinn's seizures.

Approximately one in every 100 Canadians has epilepsy and one third of people with epilepsy will continue to have seizures despite taking anti-seizure drugs and approximately 42,000 children/youth in Canada are living with epilepsy.

When a child is experiencing the frequent epileptic seizures that Quinn was, Dr. Lewis says it can quickly lead down a path that stunts development and leads to long-term effects beyond the seizures themselves. That was the biggest fear when they weren't seeing the prescribed medication work for her.

?In 2017, when Quinn came to me and we made the diagnosis of epilepsy, we went through the standard treatment with anti-epileptic drugs for her type of epilepsy and it didn't work,? said Dr. Lewis. ?About 30 per cent of patients have what we call drug-resistant epilepsy and that means you have failed two or more medications. What started to happen with her?we sometimes see this in young kids who develop really bad epilepsy and have ongoing abnormal brain activity?she started to lose her developmental skills. It's called regression, if a child is able to walk, they start to stumble or they can't use their hands as well as they had been, or their language starts to deteriorate; we started to see that with Quinn. It's due to excessive electricity in the brain that doesn't allow the brain to communicate with in itself and it starts to lose its skills and prevents a child from learning new skills. That was the real big concern.?

Eventually, Carrie broached the subject of treating Quinn with medical cannabis oil and Dr. Lewis agreed to try it.

?It came out of my own research and before my daughter was diagnosed with epilepsy, I was aware that CBD was being used in the medical world,? said Carrie. ?I always did have it in the back of my head when she was diagnosed but being new to epilepsy I wanted to follow the guidance of the doctor and I think we just got to the point where we weren't seeing success with the typical AEDs that are prescribed to kids with epilepsy. I didn't view medical marijuana in a negative light, it didn't have a stigma to me, it was an opportunity and a potential way to control seizures, so why not try it??

Having dabbled in medical cannabis before with patients, Dr. Lewis was well-versed in the topic enough to commit himself to understanding what it could do for a kid like Quinn, which ultimately led to him and Carrie agreeing to go down that path.

?Really it was Carrie who first brought up using cannabis; concurrently, I had been working with cannabis for some patients over the last few years prior to that but had never really gone out and prescribed cannabis to a lot of people,? said Dr. Lewis. ?For me, it was a bit nerve-racking as well. I didn't have a big sample of patients that I had used it on. Carrie and I had a few conversations about it and she had done a lot of work on it and knew a lot about it at that point. We went through the risks and benefits of starting it at that time and ultimately concluded that the other medications weren't working. Given all the data we knew at that time and that I had explored with my colleagues, we opted to try it for Quinn.?

After one week of starting CBD-dominant medical cannabis, Quinn's seizures stopped, and she steadily began to walk normally with no falls?something she hadn't done in nearly two months.

?Obviously we were super emotional making that decision because it wasn't the case where we were able to take her off her other drugs right away, you have to kind of do a slow wean and just doing that and with the addition of CBD, her having the ability to walk?which we hadn't seen for weeks?was an, ?oh, my God' moment and just solidified for us that we made the right decision,? Carrie said.

Dr. Lewis and his colleagues realized quite quickly that medical cannabis was working for Quinn and that it exceeded their expectations with the positive results and ultimately had a greater effect than the regularly prescribed medication for epilepsy.

?There are variations of responders, some patients are robust responders and respond very quickly while some take a lot of time. For Quinn, she responded to this within a couple days,? he said. ?In terms of reduction of seizures, it happened nearly right away and within one week her seizures stopped completely. Not only that, but her clumsiness and inability to walk normalized and she returned to her normal movements, language, and cognition. Even more so, we tested her EEG before and after cannabis and the EEG?which measures the electro activity?became normal within six weeks of starting cannabis. That's not normal, we don't see that a lot?there's very few epilepsies that you treat with a medication and the EEG comes back normal when it's that bad. That was one of the biggest things because the more your EEG is normal, the better chance you have for your brain to develop properly.?

However, Quinn's seizures returned one year later and Dr. Lewis suggested adding THC (or Delta-9-tetrahydrocannabinol) to Quinn's treatment, as THC can work with CBD to stabilize the endocannabinoid system?a system that is believed to play a role in the development and/or exacerbation of some epilepsies.

?She's over a year seizure free and just had her sixth birthday in November,? Carrie said. ?She's a twin, so when she had the diagnosis, we just wanted to ensure her milestones were on pace with her sister's?that was our baseline. Throughout everything she continued to hit her milestones and her development was never significantly impacted in a long-term way. She's just a regular kid.?

Seeing firsthand what medical cannabis can do, Carrie wants people to understand that it's not just the drug it's been stigmatized, as it's so much more, and because of it her daughter is able to live a normal life.

?The stigma is there simply because marijuana is a drug and it's a drug that was historically used to get high recreationally,? she said. ?There's certain associations people have with marijuana and the negative connotation of getting high, and I think it's a generational stigma. Now, I think it's more readily acceptable in my generation and younger, especially now that it's been legalized. I think it's the way that it was always portrayed and the association of what a person who smokes marijuana looks like.?

Dr. Lewis has treated a couple individuals with medical cannabis, with Quinn being the most prominent in terms of positive results. It's fully changed his outlook on medicine and has led him to committing himself to research in that realm.

?It was a paradigm shift for me,? he said. ?It has defined my medical career, it's defined where I'm going, and it's completely changed how I've looked at medicine and how I was taught medicine. I'm not exaggerating, there were things leading up to Quinn, but then certainly thereafter and where I am today has to do with my experience with Quinn and what I was privy to in having that opportunity to work with her. It has shifted everything for me.?

As for how he sees the stigma, Dr. Lewis doesn't see it going away in his lifetime, but he's hopeful with stories like Quinn's being told, it will lead to a wider acceptance in the medical world because it can have a difference on someone else's life the way it did for her.

?At this point in time, there's certainly a trend towards destigmatization and broader acceptance. I would say that's the case both due to surveys that have been published and my own personal experiences with colleagues,? he said. ?I don't think we'll ever eliminate

the stigma through the next two generations, I think it will take a real change of the guard for this to be completely destigmatized, it's hard to eliminate that when people were born in a culture where this stuff was vilified completely. It's going to take time, but if I were to classify it right now, I'd say there's a relaxed stigmatization. It's still there but there's a relaxation around the stiffness of the stigma and there's a big more openness to it now. You have a greater number of individuals now who are willing to listen rather than shut it out before they've even heard it.?

In 2021, Dr. Lewis published a paper in the Canadian Journal of Neurological Sciences on Quinn's case and four others with pediatric epilepsy who responded to the addition of THC to their regimen of CBD-dominant medical cannabis?all with promising results.