

## Living with Epilepsy

MJ

It was 4 years ago now; our son MJ was 3. He had fainting spells, staring off into space. His head would droop, and he would look like he was falling asleep. He constantly had dark little circles under his eyes, always looking fatigued no matter the amount of sleep he got. We had a huge scare; he collapsed and fell asleep on us. It presented like a Diabetic Coma. We were so scared and panicked. We rushed him to the emergency room at Chatham Kent Health Alliance, where they performed many tests. The on-call doctor ordered an EEG when he observed MJ to be sound asleep and suddenly began screaming and thrashing.

Our little guy was referred to the Neurology Department at London Health Sciences Centre, where more testing revealed signs of seizures. It was MOTHER'S DAY of 2017 the formal diagnosis came. Things were so blurry to us, so emotional as we tried to figure out this new pathway of care for our son. I knew of epilepsy and had some training with work. I felt an urge to reach out to someone. I knew that I did not want our family to be alone. I knew that I wanted support for MJ, someone more qualified than me, to teach us, advocate with us and educate his teachers, peers, and school.



We found the contact information for our local epilepsy educator from Epilepsy Southwestern Ontario, amongst the piles of paper from one of our Neurology appointments. We called the number and have been connected ever since. We have enjoyed playdates, activities and have connected with other families. PURPLE day is a big deal at our house! We rally behind MJ and wear purple, we put up posters at school, work and encourage family members to wear purple.

This journey with a loved one with epilepsy has taught us; patience, it has taught us acceptance of someone different than ourselves. Our little MJ, now 8 is a whole lot stronger, resilient than we ever imagined. We would like to encourage other families to reach out, talk and share their stories.

We want you to know that you are so brave, strong, and courageous. You can do anything you set your mind to. Do not let epilepsy rob you of your JOY in the moments doing the things you love!