



Our family's journey

How to thrive amidst the chaos

Dark Times

- At the age of 6 months, Adam was diagnosed with a benign brain tumour – choroid plexus papilloma
- After excision, he developed hydrocephalus
- Developmental milestones were delayed in part due to anti-seizure medications which he took for 9 months that made him incredibly sleepy.
- Physio and occupational therapists came bi-weekly to assist us with exercises to improve his chances of "catching up"
- At the age of 3, he had his first seizure



Diagnosis

- His formal diagnosis was partial complex seizures and the frequency was hard to determine as initially they lasted seconds
- Tegretol was used between the ages of 3-5 and this worked incredibly well.
- We were getting ready to wean him off after he was seizure-free for 2 years, when he had a seizure.
- We were incredibly disappointed but soldiered on

Rough Patch

- Ages 5-7: Prescribed Epival as an add-on in an attempt to control the seizures.
- Seizure control was difficult; aggression ensued and learning was impeded
- The hydrocephalus increased slightly and Dr. Rutka recommended that Adam not engage in contact sports. The possibility of a shunt was discussed.
- Meds change after hospitalization due to "overdose" supratenuation
- Adam was assigned a teacher's aide and given an individualised learning plan in grade 2. We refused the school's suggestion that he wear a helmet in the playground.
- He had braces designed for him in order to reduce the "toe-walking"

Adam's reaction

- Rarely complained – super compliant to therapy
- The braces were worn 24/7 and they were hot and made shoes difficult to put on
- He was incredibly brave when it came to going to appointments for blood work, MRIs, hospitalizations
- In grade 5, when he was hospitalized for a grand mal seizure on Father's Day that left him temporarily partially paralysed, he apologized to his dad for ruining his special day.

Scary Times

- In grade 7, first episode of status epilepticus
- Suddenly, our world became much more complex
- Hospitalizations ensued over the years
- Strategies to keep Adam safe
- New rescue meds prescribed

Effect on the child and family

- Psychologically, having a child with special needs places stress on everyone
- Lots of appointments and tests (neurosurgery, neurology, physio, OT, psychologists, orthopaedics, sleep-deprived EEGs)
- Over the years, we researched best options for treatment (meds, brain surgery, implant). These investigations meant more appointments, tests and work-ups, hospitalizations for Adam
- His problems at school were handled well. He had assistance from several specialists ranging from Mme Caroline (special ed) to school OTs to help him with his handwriting.
- We engaged a private physiotherapist, Catherine Patterson, to improve his core strength.
- His IEP followed him to high school. Special Ed and particularly Lisa Weekes were helpful in his transition and success at Emily Carr Secondary School

Instilling a Positive Culture

- Everyone has their way of coping over the years – ours was unique.
- Travel was the answer to counter tough times
- Lots of people could not understand our decision to travel around the world with a child that has epilepsy and questioned us

Our Strategies for Coping

- Never lose hope
- Embrace life despite personal challenges
- Ask for help – friends, family, hospital staff, ET, school specialists
- If given advice that doesn't sit well with you, question it
- Be very involved with the school (elementary and high school)
- Sign up for specialized camps (Camp Cooch)
- Advocate for services within the school and in the community
- Teach your child to advocate
- Promote independence (balanced with safety)
- Have things to look forward to – walk in the park, a new book to read, bubble bath, road trip
- Open up your world – read, explore, learn about other cultures

Bright Future

- Adam is graduating from high school
- He is bilingual
- Will be attending a "Me to We" leadership camp in August
- Was accepted to Seneca College in Tourism Services Management
- He is compassionate and helps others
- Volunteers with many organizations

