I just can't believe what my little boy has been through. Yet never once has he complained. He's just incredible.

This is Maverick x

For all Maverick has been through over the past two years, I look at my son and feel immensely proud of how he's handled all the tests, scans, hospital stays, medical appointments, medication trials. Never once has he complained. It's like he understands we're all trying to find a way to get his seizures under control.

Maverick lived a normal life up until he was 5 years old. One night as he was asleep in his room, and I was putting to bed our youngest son, I heard a strange noise – like coughing. *Oh no, someone's ill, I thought.* As I walk into Maverick's room, I noticed he didn't look right. He had this little patch next to his head that looked like vomit. I rolled him over and kept thinking, what's happening to my son?

His eyes were opening and closing. He was mumbling and chewing. I thought he may have been having a stroke! I called my husband – **Something's happening to Maverick. He's not responding to me.** My husband hung up. I now know he was calling an ambulance and driving home. I called my mum as she has been a nurse for over 20 years – she simply said *"hang up, call an ambulance."*

I couldn't understand what was happening to Maverick. I was in shock. I was numb. Looking back Maverick's first seizure was over 8 minutes long. But it took months before we were finally told Maverick has Benign Rolandic Epilepsy.

Over time Maverick was regressing developmentally. His school was concerned he was falling behind. And so we began to ask more questions and Maverick underwent more tests. Finally, we were told he most likely has a very rare epilepsy – CSWS (continuous spikes and wave activity during sleep, which lead to seizures and developmental regression).

It's hard to explain his epilepsy to others when you're trying to understand it yourself. **Now we explain it as having constant seizures, but you can't see them.** He also has other seizures people do know of – absence and tonic clonic seizures. Sadly, there's no drug that can control his seizures.

I remember the neurologist telling us we would need an Epilepsy Management Plan for home and for Maverick's school from the Epilepsy Foundation. **It has been amazing having the Foundation's support.**

The advice and guidance they've given us. They put us in contact with another family who also were on a similar path as us. Just to be able to talk with someone who knows what we're going through is comforting. And with Maverick's constant changes, they change his Epilepsy Management Plans accordingly. They've provided education and training to his teachers so they know how to care for him. **To have someone you can talk with – the Foundation has been and continues to be an incredible support.**