

"I've learned while I can't take epilepsy away. I can walk beside them through it."

This is Rebecca's story - mum to Chris, 26 years old, and Alex, 23 years old. Both have epilepsy.



Around the age of 14, my sons started having shoulder jerks and "glitches" as we called them. At the time we were told it was due to gaming, staying up too late, school stress... Looking back, it was juvenile myoclonic epilepsy, but neither we nor the GPs had any idea.

Finally, in late 2021, both boys were diagnosed with juvenile myoclonic epilepsy.



Chris also suffers from nocturnal myoclonic seizures, which cause violent jerks during sleep. He'd often be injured from these, waking up with dislocated shoulders or falling out of bed, and has required reconstructive surgery on both shoulders due to ongoing damage. This has been a major setback for him, both physically and emotionally.

Both boys also experience cluster seizures, tonic-clonic seizures, and focal seizures (both aware and unaware), making their condition complex and difficult to manage.

Hearing the diagnosis felt like the ground shifted beneath me. My first instinct was to understand what this would mean for their futures, their independence, and their wellbeing. I wanted answers, but more than anything, I wanted to protect them.

Living with epilepsy has been a family journey filled with emotional highs and lows. I didn't realise how life-changing it could be. I didn't understand the complexities of it. I never knew that anxiety and depression, panic or fear of having a seizure was a very real thing.

It has taken a real toll on me - emotionally, mentally, financially and physically. There have been panic attacks, sleepless nights, arguments, and moments of deep exhaustion. I've had to learn how to stay calm during seizures, even when I'm terrified inside, and then allow myself to cry later when the moment has passed. It's a constant emotional balancing act.



Epilepsy is isolating. No one truly understands the constant worry and sadness I carry for what my sons have endured and continue to face. People try to relate, but unless you've experienced it, it's hard to grasp the weight of it.

Though their seizures may be similar in type, the support each of my son's needs, especially during and after, is very different. I've learned to respond in ways that meet their individual needs, even when the situation is unpredictable and intense.

A therapist once told me to switch off my phone and take a weekend away. I remember saying,

"Did you hear me? Both my sons have epilepsy. If something happened while I was away and unreachable, I could never forgive myself."

That's the reality I live with. And there's a reality my sons live with.

Epilepsy has impacted their lives in significant ways. It's affected job opportunities, friendships, and their confidence at times. There have been moments where they've had to shift direction, let go of plans or dreams they once thought would be part of their journey. That's been hard to witness, but they've adapted, redefined their goals, and found new paths forward.



They've experienced stigma and discrimination from misunderstanding, fear, judgment. They've had to leave jobs they loved, because their seizures made others uncomfortable. They've faced assumptions about their capabilities, been excluded from opportunities, and had to work harder to prove themselves. The emotional toll of being treated differently - of feeling like a burden or being misunderstood, has been just as heavy as the physical toll of the seizures themselves.

Despite everything, our bond is unbreakable. They know I'm always in their corner. This journey has tested us, but it's also made our connection stronger than ever. I am immensely grateful for the relationship I have with them both. They are resilient, tenacious, caring, independent men who really do inspire me more than they know.

The Epilepsy Foundation is also in our corner. From the moment I reached out, I felt seen and heard. They've been more than just a resource. The Foundation has been a lifeline.



They not only provide practical guidance and education, but also emotional support and advocacy. They understand the complexities of epilepsy, not just the medical side, but the personal, emotional, and social challenges that come with it. Their team is compassionate, knowledgeable, and genuinely committed to making a difference. Thanks to them, I have felt less alone and learnt an awful lot about epilepsy. They've helped me navigate difficult moments and celebrate small victories. I'm incredibly grateful for the work they do and the impact they've had on our lives. And I hope you will consider supporting them, so other families, just like mine, receive the wonderful support we have.

Epilepsy hasn't defined my sons. It's challenged them, but it hasn't broken their spirit. They continue to live independently, make their own decisions, and advocate for themselves. Our family is built on trust, love and resilience.

Thank you for reading my story.

Rebecca xx

