EPILEPSY NEW ZEALAND
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Archie's story



FAMILY COPING WITH EPILEPSY AND GETTING ON WITH LIFE

Feisty and fun-loving Archie Milliken was just four-years-old when he had his first, severe seizure around 5.00am one morning. His Mum Alissia says, luckily, she was in his bed with him at the time so she was woken when it happened. "It was a shock as he had been completely well, so I felt certain it wasn't a febrile convulsion. Also, there was no history in our family of seizures."

Alissia carried Archie outside thinking fresh air would help stop the convulsion but ultimately called an ambulance. "I thought he was dying," she says. "As Archie's seizure went on for around seven minutes, I thought he was going to stop breathing at any moment. It was terrifying."

Archie was taken to Geelong Hospital but Alissia was frustrated with the diagnosis. "They said he must have been at the back end of a cold, so it was a virus. They didn't believe me when I said he was fine. It was a mother's intuition; I had a gut feeling it was epilepsy. It was frustrating because they wouldn't explore the cause any further as it was a one-off seizure. "

Back at home, Archie then had another seizure approximately six months later. Again, Alissia called an ambulance and she recalls saying to her husband, Stuart, that she felt this was epilepsy. "He was sceptical but I knew, so I pushed the GP to order an EEG (electroencephalogram). A sleep-deprived EEG was done at the Royal Children's Hospital when Archie did have a seizure."

As a result of the EEG, a diagnosis of Benign Focal Epilepsy was made, when Archie was still just

four-years-old. His seizures are always nocturnal, usually occurring in the early hours of the morning, and are similar to a tonic-clonic seizure, with full-body shaking.

"While it was devastating to receive a diagnosis of epilepsy, I was also relieved as it could have been so much worse, in the scheme of things," says Alissia.

Alissia explains that when Archie was diagnosed, the reality hit and she realised that this would be their life now. So she reached out to Epilepsy Foundation Australia for help. "I spoke with a Client Services support worker who recommended a special mat for Archie's bed that can detect his seizures and sound an alarm. I hardly sleep now, as I am constantly alert to whether he is having a seizure. It's a mother's life," she says, "but the Foundation was really helpful."

Archie continues to have nocturnal seizures, with his paediatrician closely monitoring and adjusting his medication in line with his growth.

Alissia says Archie can be a bit aggressive at times. "He can be very argumentative and he gets tired and frustrated easily. He may have a mood disorder, so he is seeing a behavioural psychologist at the moment."

His learning has been mildly affected too as, Alissia says, Archie has trouble with reading and handwriting, but is an average student. "However, he loves sport because it's easy for him, particularly soccer, tennis, cricket and football. It's an outlet for his energy and frustration."

There is another factor that is impacting on Archie's future prognosis. "A month after the diagnosis, Archie fell off his bike and hit his head, suffering a trauma to his skull," Alissia says. "We know that he could potentially outgrow the Benign Focal Epilepsy, however, following the trauma to his head he may now never outgrow it or there may be another form of epilepsy waiting to show itself. So it's a waiting game."

However, she is happy to say that, four years on from Archie's diagnosis, it hasn't stopped her, Stuart, Archie and his brother Harry, 10, from doing anything. "We travel a lot overseas including the United States and Thailand and Archie is going on a school camp soon. We try to live as normal a life as possible."

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