

# Every 33 minutes... An Australian's life changes.

06:00PM

just before dinner



08:14AM

onsite for work experience



04:00PM

watching AFL Grand Final



## AT THAT MOMENT...

They need the best support, information and care.  
They need the Epilepsy Foundation.  
And they need YOU.

# 06:00PM... dinner time... a little boy's life changed forever... **This is Blake's story.**

At home, sitting on the stool in front of the computer, Blake was ignoring his mum's request to get ready for dinner. As Ashlee kept asking him to stop, Blake kept ignoring her.



At that moment, Ashlee realised her son was not okay. Blake was just six years old and having a seizure that would last around three minutes. A seizure that would change his family's life forever.

While Ashlee's husband Tim called for an ambulance, she noted that Blake's seizure transformed from an absence seizure into a tonic-clonic seizure. Blake experienced another seizure in the ambulance and another four seizures while in hospital that night.

The seizures didn't stop even when he was transferred to another hospital. Blake went into status for 10 weeks. **He was experiencing seizure after seizure every single day. Over the course of a 12-hour period, Blake had 23 seizures.**

With his seizures unable to be controlled with medication, Blake was admitted into ICU undergoing a series of CT scans, MRIs and lumbar punctures to identify what was going on. The doctors were baffled, his parents were scared.

Just as the doctors were preparing to place Blake in an induced coma to give his brain a rest, Ashlee put her son on the phone to his twin brother. Blake was no longer able to talk, so his twin brother talked, sang and read. Finally, Blake stopped having seizures for about an hour. He was given medication, and with his brain exhibiting fewer seizures, Blake slept for the next 24 hours!

Finally, Ashlee and Tim were told that most likely their son has febrile infection refractory syndrome (FIRES), a condition that affects a previously healthy child after a short fever, such as a cold or flu. **A once healthy and happy child, Blake had to relearn how to use a knife and fork, go to the bathroom, sit, brush teeth, walk, talk...** This was the beginning of Blake's and Ashlee's journey with epilepsy.

While Blake was in hospital, we reached out to Ashlee to let her know of the support we could provide her and Tim. Since then, we've been by their side. Our Epilepsy Support team have helped them understand Blake's condition, created an Epilepsy Management Plan and helped secure a monitor to record Blake's brain activity while asleep at home. We also helped Ashlee write a letter explaining her son's condition to family, friends and school, and provided Blake's school with resources and information so they're equipped to care for him when he has a seizure. Most importantly, we've helped Ashlee understand that her son is a normal happy 9-year-old boy who happens to have epilepsy.

**Donate today so families like Ashlee's can continue to receive life-changing support, information and care. Visit [www.epilepsyfoundation.org.au/1every33](http://www.epilepsyfoundation.org.au/1every33)**

# 08:14AM... a new day turns into a new chapter... This is Indy's story.

When Indy was in Year 9 in 2018, she decided she wanted to become a plumber. With her heart set on her new career path, Indy studied hard, excelling in her subjects. The time came for her to do work experience and with great excitement she set off early to get to the worksite.

**At 8:14AM Indy suddenly collapsed, falling backwards, hitting her head. By 8:30AM her distraught father called Indy's mum, Bianca, to tell her their daughter had been admitted to hospital.**

The doctors were unable to tell Bianca what had happened to her beautiful daughter. Reflecting back, Bianca believes that Indy may have been experiencing seizures earlier than that day. When Indy was younger, she would act aggressively and other times she would ignore her mum. For Indy all she wanted to do was sleep. *"I just wanted to sleep all the time. Looking back, it probably was me having seizures in my sleep. I never understood why I constantly needed to keep sleeping."*

As the days and weeks passed, Indy's collapse was soon forgotten. Life went back to normal. Yet as the months went on, Indy's parents noticed that she was ignoring them. Her excellent grades began to slide, her ability to study was being affected.

**Unbeknown to Indy and her family, she was experiencing absence seizures and was getting progressively worse. Indy had become very forgetful, tired and constantly yearned to sleep.**

Life changed for Indy. As Bianca shared, *"2020 had become the year of the hospital."*



Finally, Indy's parents were told their daughter was having multiple seizures a day and that she has epilepsy. Indy was also told that her dreams of becoming a plumber were no longer possible.

**That day, 21 May 2020, was the beginning of Indy's own journey with epilepsy.** Soon after, her parents contacted the Epilepsy Foundation. We have been right by their side, providing them with the support, information and care they need to understand and manage Indy's epilepsy. And although Indy can no longer pursue her dream of becoming a plumber, she is now completing her studies in childcare.

Having a loved one diagnosed with epilepsy can be a lonely journey. While extended family and friends mean well, often they're not fully aware of the worries and concerns parents like Bianca face. We're here to answer every question a parent has about their child's epilepsy, sending them vital resources and information. We regularly check to see how they are doing and how they're coping. We make sure they never feel alone, and if they're struggling, we're ready to assure them. We're here for them.

**You can help families continue to be fully supported with the information and care they need. Visit [www.epilepsyfoundation.org.au/1every33](http://www.epilepsyfoundation.org.au/1every33) and give today.**



# 04:00PM... the 2009 ALF Grand Final Day was just the beginning... This is Fergus' story.



In 2009, then five-year-old Fergus was playing with his Lego as he watched the AFL Grand Final. The day started off like any other Saturday except that he had a terrible headache. His mother, Meg, gave him a painkiller to help. But as the clock ticked to 4:00PM, Fergus started feeling weird and not himself. He became drowsy, and within a few minutes he was unconscious ...

The next thing Fergus knew, he was in the Royal Children's Hospital surrounded by doctors and nurses. His distraught parents were desperately trying to understand what had happened to their little boy. **They were told he most likely has Cavernoma, a rare condition that causes bleeds in a person's brain.**

The following months Fergus continued to experience weird feelings, headaches, strange noises. It was not unusual for him to spend time in the school's sickbay. The bleeds in Fergus' brain were causing multiple seizures, especially at night.

Meg felt helpless. While the doctors were sympathetic and provided great medical care, she wanted to know how best she could help her son manage this condition. She wanted answers, yet few were forthcoming. **How would this diagnosis of Cavernoma affect her son, his future, his dreams?**

When Fergus was in Grade 5, he underwent his first brain surgery. As he recovered, he and his mum applied for him to become Grade 6 School Captain. Much to their delight, Fergus won the vote. Fergus had shared with his classmates what he had just gone through. He showed them his scar and some pictures of his brain. Fergus let them know that *"I don't have deficits. I'm not brain-damaged, I'm normal. I can't run around and play outside with you for a while. But it's really important that you don't make an assumption. It's not going to make me weird. I'm normal and I've come through this okay."*

**For many years Fergus was seizure free. That was all to change in 2020. Within a few weeks Fergus had four grand mal seizures. Tests showed that the bleeds in the brain had returned.**

In May 2021, Fergus underwent his second brain surgery. All went well, however tests showed seizure activity. Fergus' and Meg's journey with epilepsy began on the day of the 2009 AFL Grand Final. Fergus is adamant that Cavernoma won't stop him from potentially becoming an astrophysicist. Meg believes that her son will one day help find a cure for cancer, possibly even for epilepsy. **We will be right by their side, providing them with the support, information and care they need now and into the future.**

Communication is critical for people living with epilepsy. Our Epilepsy Support team are a phone call or email away. And they contact parents like Meg to ensure they have the support, information and care they need. We communicate with schools, specialists and hospital staff to ensure that the families understand the diagnosis, medications, level of care and so much more. We help parents create and understand the Epilepsy Management Plan, so that when their child has a seizure they confidently know what to do.

**We balance providing practical help with emotional support for families. Yet we need your help. Visit [www.epilepsyfoundation.org.au/1every33](http://www.epilepsyfoundation.org.au/1every33) and donate today.**