

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 and donate today.