

Julian's Story



Epilepsy has been a big part of Julian Walker's life since he was just six years old yet he has managed to get on with life and, as an adult, he finds fulfillment as a volunteer.

Managing long term epilepsy to lead a fulfilling life

Julian's mum, Susanna, says he had his first seizure at age six when the family was driving home from Queenscliff one night. "Julian was asleep in the backseat and I noticed his eyes just sort of fluttering. It was strange and we probably didn't think of it as a seizure at the time."

After that, she says, he didn't have a seizure for a while. "Then, I noticed when he was waking up in the morning he had bitten his tongue, so I realised he was having seizures during the night."

Susanna says they then saw a neurologist who prescribed medication, which didn't really help him but Julian didn't seem to have many seizures over the next few years. However, they really accelerated when he was about nine years old. "We travelled together to England to visit my mum and it was then that his seizures got really bad. He was having tonic-clonic seizures at this stage. On the plane coming home he had about 30 seizures; it was a terrible time. I believe it may have been jetlag triggering his seizures."

According to Susanna, Julian then went straight into the Austin Hospital when they came back from overseas and was diagnosed with Autosomal Dominant Nocturnal Frontal Lobe Epilepsy, a rare form of epilepsy that is usually genetic, or inherited. Susanna explains, "Julian's father, Michael, had seizures which were never diagnosed as epilepsy and were different, but that's probably where he got it from."

Susanna says despite the diagnosis and the fact that Julian was then able to go onto appropriate epilepsy medication, the pattern and frequency of his seizures changed often and they were difficult to manage. Unfortunately, she says, things would only get worse.

"His doctor said his seizures would worsen with age. When he was a teenager they did get worse,

but he handled it well and just got on with it."

Susanna explains that at that stage Julian was allowed to drive because his seizures had always occurred at night. "Then in 2011, he had one when he was driving and crashed the car. Fortunately, no-one was injured in the accident but Julian did hit his head."

"In 2012, we travelled to Lebanon to visit Julian's brother, Hamish, who was living there at the time. When we got back, Julian's epilepsy got really bad and he ended up in status epilepticus, which may have been brought on by jetlag, and he had to be put into an induced coma. The first coma didn't work, but the second one did stop the seizures. Then his dad died from cancer in August that year as well, so it was just a really bad time all round."

Status epilepticus is a dangerous condition in which epileptic seizures follow one another without recovery of consciousness between them.

Susanna says unfortunately Julian now has a brain injury. "No-one knows how that happened, if it was the effects of the ongoing, severe seizures or the car accident and whether this was compounded by grief associated with his father's sudden death. His brain injury affects his speech and memory, his ability to think things through and understand concepts, and I think it has caused him to be depressed at times."

"We've been told he won't ever be able to work, but Julian is still confident that he can work and is trying to find a job. I'm sure there would be someone out there who would employ him and there would be something he could do."

"Unfortunately Julian's seizures, which still mostly occur at night, are not under control, so it means he may not be able to attend work early in the morning."

Now 33, Julian manages to volunteer at Epilepsy Foundation Australia and has been a regular in the fundraising department for the past three years. He assists with data entry work and handling receipts for door knock appeals and according to Susanna he loves it. "Working at the Foundation has really helped him," she says. "He is a different person when he comes home."

She also says the Foundation has been enormously helpful with information about epilepsy. "We have looked up the website lots of times and found information that has helped us understand epilepsy and Julian's specific condition."

