

Epilepsy in Australia

Submission to the community affairs reference committee

Our Family was first impacted by epilepsy on January 1st 2020 when my then 14-year-old daughter had her first tonic clonic seizure (previously called grand mal seizure). She fell to the floor convulsing and turning blue out of nowhere, with no family link to epilepsy we were at a loss whilst waiting 40 mins for an ambulance to arrive on one of their busiest nights of the year. We live in a rural location but it's only 40 minutes away from Geelong - Victoria's largest regional town, she remained unconscious the whole time. An ambulance trip to the ER ended with us being told to go home with nothing more than the explanation that "anyone can have a seizure" and an outpatient appointment to follow up. The message was the same at the outpatient appointment and **we agreed to see the same doctor at his private rooms** - due to her age he was a paediatrician. We chose this path **to try and accommodate 1 doctor overseeing our daughter's care.**

Five months later we would present to the same ER with our daughter experiencing a 2 day complex migraine and discovering she had a cyst in the brain - and told that it was unrelated to her seizure and to return home and continue to see her paediatrician. 7 months later she had her second tonic clonic seizure on Christmas Day and by the end in January 2021 after two more TC seizures she would finally be diagnosed with epilepsy and put on anti-seizure meds.

We continued under the care of her paediatrician as **the epilepsy clinic at university hospital Geelong's neurology department does not see patients under 16 years of age and private neurologists would see not see anyone who wasn't an adult.**

2021 was taken up with anti-seizure medicine, increases, reductions, and changes to new medications because of the side effects noted whilst continuing her high school education. In November she finally had a follow up with the RCH Melbourne about the cyst in her brain confirming it had nothing to do with her seizures. In 2022 she had her first appointment with a neurologist and was officially diagnosed with Juvenile Myoclonic Epilepsy (JME) - a type that starts in teenage years and has 3 different seizure types. Myoclonic seizures are uncontrollable jolts of the arms or legs - causing her to put food in her hair whilst eating or "throwing" a drink at the cinema. Absence seizures can go unnoticed due to only happening for a few seconds but often looks like staring blankly and being unresponsive.

It took;

13 months from her first seizure to being diagnosed with epilepsy and starting medication.

18 months to get a follow up with the Royal Children's Hospital regarding the cyst in her brain.

Nearly **2.5 years to see a neurologist** and have a formal diagnosis of JME.

Nearly 3 years to get to a dose of 2 different medications that **control her seizures** with the least amount of side effects.

But **epilepsy is so much more than seizures** and the physical damage caused by falling unconscious. My daughter suffers daily with extreme tiredness, lapses in the ability to concentrate, bad memory, brain fog, sore gums (from the medication) and there are untold side effects due to come from long term drug use.

No one comes and tells you epilepsy is a disability and yet she lives a different life to the one she had before it - we live rurally and she isn't allowed to drive. She is half the person she was academically and whilst she is still able to study it is so much harder for her to do so and our health team says that these changes could be from seizure activity or the medication but there is no way to tell.

I still don't know if she has a "chronic health condition" or a "disability" under the law but I know she requires huge amounts of assistance to live a life.

It was a struggle for her to complete high school but she did so at the end of 2023 and then needed rest so took a GAP year - something I never thought I'd advocate for but she was completely exhausted. During 2024 she continued to pick up some **casual shifts at her local IGA but could only do so when we were able to drive her there as we have no public transport in our rural area.** As she was incapable of full-time work, we did not apply for jobseeker payments knowing that she was not looking for work and we continue to support her. **I tried my hardest to navigate the Services Australia website looking for ways in which she could get some assistance but simply got lost between all the links and jargon** and found myself unable to call anyone for assistance. We were **paying \$70 per month for medications**

- something she could not afford herself. I couldn't find a way where she qualified for a health care card to reduce the cost. I ended up reaching out to the National Epilepsy Support Service NESS to ask about subsidised taxi fares because we live 30 minutes away from the nearest public transport and she is not allowed to drive, but I was told she was ineligible because she "must experience more than 12 episodes a year, longest period between consecutive seizures must be 2 months or less" under the scheme.

So our health goal of **stopping seizures and keeping her alive now prevented her from some assistance but didn't stop her from being banned from learning to drive!**

2025 saw our daughter start university and become a full-time student and finally she was able to get a health care card - not based on her diagnosis but because she is a low-income earner. Her medication now costs just over \$21 a month. Her struggles continue with study but university life seems more open to acknowledging her extra needs and accepts the word of her neurologist saying she needs assistance. To get to uni I get up at 5 am to drive her to the station and she commutes up to 5 hours each day to study. She is too scared to move out of home as missing a dose of medication means she will have a tonic clonic seizure before her next dose is due - the last one (her 17th) landed her in hospital again with 5 stitches to her forehead.

Right now we are able to support her but her independence is the cost- unlike other 20 year olds she rarely goes out not only restricted by not driving but by tiredness that is bone deep, lots of misunderstanding, fear of seizures and of missing doses of medication.

The epilepsy community needs clarification and inclusion about its position as a disability- not just in seizure types but the ongoing effects of anti-seizure medication, uncontrolled activity in the brain, damage to the brain and loss of jobs due to misunderstanding of the condition. People who are prevented from driving due to their epilepsy who live without public transport should also qualify for taxi assistance

I hope our story helps you understand the daily struggles for people with epilepsy that happen outside of seizures and the difficulties they face in seeking assistance when their condition isn't fully recognised or understood. Trying to access help is diabolical because where do you even start? Websites can help those in the system but it blocks you from having the knowledge of how to begin and there seems to be no one to ask. People with epilepsy fall through the cracks and rely on families and restricted, smaller lives. That breaks my heart.