Submission to the Community Affairs Reference Committee
Epilepsy in Australia

My husband was diagnosed with Epilepsy at the age of 19, in the early days of our relationship. He suffers from generalised onset, tonic clonic epilepsy due to a non-functioning migrated shunt that was placed when we was a baby.

Day to day he is a very normal high functioning person. He holds down a full time job. He cares for his family. When well controlled he can still drive a car. The neurosurgeon we once saw to investigate the possibility of removing the shunt was amazed to find that he had minimal impairment from how badly displaced his shunt is on scans.

But not every day, and not every year is the same. In the 19 years that he has suffered from epilepsy he has had varying degrees of epilepsy control. Long periods (years) of not driving due to medical revocation of his drivers licence. Significant struggles with fatigue and insomnia, problem solving, short term memory loss, headaches, tremors and mood swings. Some of these due to the long lasting after effects of seizure episodes and some due to high doses of medications used to attempt to stop the seizures.

He has never been eligible for NDIS. His epilepsy is not classed as disabling ‘enough’ to qualify. It is lucky that I am also a Registered Nurse, I’m not sure how any normal person would manage. I have been able to work my shifts around his seizures, taking breaks off work and swapping shifts around with other nurses so that I could be at home to support him. I also have the skills that nursing has taught me when I have to manage the violent seizures he has. We have no other help.

He wears an epilepsy detection monitor (which we pay for the device, and the yearly membership fee) which calls me when he has a seizure, it has done so whilst I’m on nightshift at work. I have had to rush home and once my 7yr old had to call an ambulance whilst I was not at home.

After a seizure he requires several days off work- more if he is hospitalised. The entire first 24 hours after a seizure he sleeps. The week following he experiences short term memory loss, anything that happened the week prior and that week is gone. He needs constant watching and redirecting to remind him what and where he needs to be and what he was planning on doing in that moment. He also suffers from extreme muscle aches and fatigue due to the tonic-clonic movement that his muscles have experienced. He cannot walk more than a short distance until his muscles recover. As well as the soreness in his mouth from having bitten his tongue and the marks on his hands where his fingernails have dug in. And this is if his seizures are only minor. He has hit his head, and once dislocated his shoulder during a seizure requiring hospitalisation.

As we both work full time, and earn a decent living we do not qualify for any government assistance. We pay full price for medications and appointments. There is no help with transport costs when he cannot drive. No discount on public transport, buses, trains or taxis. After a seizure his chances of having another within the week are very high. He cannot wait on his own at a bus stop, or on a train station as he has no warning that a seizure is going to happen. He could be alone with nobody to help, or worse fall onto the train tracks. So public transport, other than taxis is not an option. Every seizure takes away his independence for a time.

He does not meet the criteria for the Taxi Transport Subsidy Scheme as he has less than 12 seizures a year. But each time he loses his licence it is gone for 12 months or more. One seizure is all it takes to lose his licence. He can no longer drive himself to work, or his children to school. I become the taxi service for the whole family. The eligibility for the criteria of the Taxi Transport Scheme needs reviewing. The possibility of one seizure on a train platform, or alone at a bus stop beside a road is one too many. My husband has no aura, and does not know a seizure is going to happen so cannot get himself to a safe place. In fact, sometimes he walks towards danger when confused prior to the seizure. It is not safe place to be. There needs to be an ability for the medical practitioner to stipulate their own reasons on the application.

Recently his neurologist has retired. We have been on a waitlist for a new neurologist. Even going privately and after recently being hospitalised last year for his epilepsy, we have waited over 18 months for an appointment. We live in a metro region and access to neurologist is an issue, it should not be.

There needs to be more community awareness and workplace awareness surrounding epilepsy. We have had issues in the past with his workplace not understanding his inability to return to work the few days after a seizure. They did not know about epilepsy action plans until we educated them. They are often not understanding of the need for him to manage stress and fatigue levels- which are high seizure triggers for him.

This is our experience of epilepsy. Little to no government support. High cost medical treatment. Isolating due to transport limitations. A diagnosis that sometimes is and sometimes isn’t a disability. And a community that does not understand the burden.