Senate Inquiry into Epilepsy in Australia

19 March 2026

Dear Committee Secretary,

I would like to submit my experience and challenges to the Senate Inquiry into Epilepsy Australia. This is my experience since being diagnosed with epilepsy at the age of 47.

I was living in a regional area in northern NSW, . My diagnoses occurred during the Covid pandemic. My first clonic tonic seizure was at night, and I was admitted to I was released with the advice that “these things happen sometimes” and not to worry about it unless it happens again.

I went back to driving a Heavy Rigid vehicle, the library truck for

The seizure did happen again, luckily while I was not driving a HR vehicle. The second clonic tonic seizure was on a windy road, my partner, at the time, was driving and I had another clonic tonic seizure in his vehicle. I was admitted to and this is when the tests began.

After the tests – EEG, blood tests, brain MRI, I was sent to a Neurologist at the Gold Coast, . He explained that it may have been due to a bad case of chicken pox/meningitis that I had when I was younger.

He was very good at explaining the diagnosis and asked if I had ever had an Aura. I didn't even know what an Aura was. However, after his explanation realised that I had had many Auras through my 20s and beyond.

The Auras usually occurred when I was tired, filtered light, windy roads, hungover. I just thought it was something weird that happened – I would pull over and let it pass.

I am now successfully medicated and living in a different rural area . I now see a Neurologist at St Vincents, Darlinghurst , she is also extremely good and has the best empathy and understanding.

The challenges

Regional areas - Why did never run the tests initially? I was involved in driving a HR vehicle, and this could have been fatal if a second seizure occurred while I was driving.

Regional - Living in a regional area particularly - I have noticed the ignorance and misunderstanding around Epilepsy. Epilepsy is not always the full clonic tonic seizures.

Medication – I have been lucky that the medication has worked for me. I can drive, after some periods of not driving, and I have my independence. Epilepsy diagnosis has not disabled me from what I want to do.

Medication – Some people do not understand that epilepsy medication is for life. I did try Keppra, it made me feel sick and caused Auras. I returned to my current medication of Tegretol.

When I was first diagnosed, I was embarrassed to talk about Epilepsy. I think because of the images/assumptions that go with epilepsy. Now it is something I can talk about. However, there is always people who are ignorant and just don't understand. Some people have even questioned my diagnosis??

What would make things better

Education – I have had people compare epilepsy to cancer. I often explain that I am on the medication for life.

Education – I have told people I have Auras and they laugh, as they think it is just some hippy explanation. I have changed to saying a Medical Aura. Most people who I talk to, who have no understating of epilepsy, have no idea what a Medical Aura is.

Community awareness is better than 1970s; however, it still feels like epilepsy is something that no one wants to talk about. Better funding for epilepsy would be great, like the funding Cancer research receives.

Epilepsy Action Australia – I had a nurse tell me about this organisation. I rang them and talked to one of the nurses. Also, extremely helpful. She helped me with the questions and even told me about applying for money from my income protection. I would not have thought of this initially. It was all very overwhelming being diagnosed.

Neurologists – both neurologists that I have seen have been amazing. I am a public patient and would not be able to afford these specialists as a private patient. I am happy with the public treatment I receive.

Medication – I am aware of the long-term effects of Tegretol, inc. Bone health, dementia However, it works for me – so what are my options? I can drive and I can live my life now.

Regards