

Driving- VicRoads

To prioritise, my biggest struggle in terms of my diagnosis of epilepsy came with VicRoads. After my second seizure in October 2024, I was told not to drive straight away as the procedure is 6 months. I managed to get a neurologist appointment in December 2024. The neurologist wrote a report to VicRoads that day. That report was not accepted by VicRoads until February 2025. This means that while I had my seizure in October, my 6-month suspension did not start until February, after already being off the roads for 3 months. My neurologist review appointment was then in June, as I was seizure free, they sent a report to VicRoads saying I was fit to drive again. VicRoads did not respond to this until late August 2025. What should have been 6 months without driving turned into 10. I cannot explain enough how horribly this impacted my life. I live in rural Victoria. I was forced to quit my job as I could not access it. While the town offers buses, these were always delayed or simply did not show up. I was often waiting for over an hour to get the bus, then arriving at my destination an hour early because the buses run so infrequently. I lost all independence and could not socialise as I was always fatigued. I was financially broken and had to rely on my family as I moved out of home for uni. I then had to regularly attend counselling sessions as I was mentally at a breaking point.

First Seizure

I was diagnosed with epilepsy in December 2024.

I had my first tonic clonic seizure when I was 18. I was sent to a rural hospital in Warrnambool, Victoria, and told I was likely on drugs the night before or had been spiked. I have never done drugs in my life. They told me I would not have epilepsy because I would have had my first seizure earlier in life. I was sent to have an MRI in case I had a brain tumour, but no further tests were conducted, nor was I told I couldn't drive for 6 months, so I moved on.

Diagnosis

After my second seizure in 2023, I was sent to a public neurologist 2 hours away, I was then waiting over 2 hours for the appointment due to shortages and I was only able to see a Registrar. I was diagnosed with epilepsy and sent on my way. The registrar specifically told me alcohol did not trigger seizures, and I was ok to drink. I later found out after my third seizure in 2024 that this is incorrect and had been the main cause for all of my seizures. In that same appointment, I was told that the medication I started (lamotrigine, 100mg daily) will increase my threshold and I would only be as likely as the average person to ever have a seizure again. This is entirely false, and I felt completely let down when I had another one 10 months later.

Community Support

Due to my loss of license after my second seizure in 2024, I had to quit my job as I cannot drive or access public transport in rural areas and suffered severe financial stress. I was isolated and scared. No one else I knew had epilepsy, no one understood it and neither did I due to a lack of awareness and education. There was no support for me, and I didn't know where to look.

As a 20-year-old girl, I want to go out with my friends, have a late night and drink alcohol without the fears of having a seizure the next day. There is no community awareness around epilepsy. Most people only categorise it as tonic clonic seizures. No one understands the fatigue, confusion, anxiety or cognitive issues it comes with. When I don't even understand what and why I'm feeling this way, how am I meant to explain that to my friends and family?

Concluding Thoughts

Today, I am 7 months seizure 3 and have been through 3 tonic clonic seizures in my life. I still don't understand my diagnosis or feelings I have, and when I explain my symptoms to the Neurologist Registrar, they said they are too hard to understand and diagnosing other forms of epilepsy (absent, focal aware seizures) is too difficult and this wasn't progressed further. I suffer symptoms of fatigue and blanking out every day, I live in constant fear I will put myself and my family through that again. I am anxious on days I wake up tired, or I'm stressed with uni, or simply have a busy week planned. I can no longer go out with my friends. No one should ever have to go through what I did, and I cannot bear the thought of ever living through that again.