

Executive Summary

Epilepsy is a complex neurological condition that presents very differently from person to person. Despite this, current medical practices and regulatory systems often treat epilepsy as a uniform condition, applying broad rules that fail to account for individual circumstances.

This submission highlights the experience of my son, who developed genetic generalised epilepsy at age 19. Although his seizures are infrequent and preceded by clear warning signs (auras), the systems governing epilepsy management and driving regulations repeatedly removed his independence and significantly disrupted our family's life.

Our experience demonstrates the need for:

- Greater recognition of the **individual nature of epilepsy**
- Improved awareness among clinicians of **all treatment options, including rescue medications**
- **Individualised medical management plans**
- Regulatory frameworks that balance **public safety with the independence and employment opportunities** of people living with epilepsy

With more flexible, informed, and patient-centred approaches, many people with epilepsy could continue working, studying, and contributing to society without unnecessary barriers.

Personal Experience

First and foremost, it must be recognised that **epilepsy affects every individual differently**. Despite this, people living with epilepsy are frequently governed by systems and policies that treat the condition as though it is the same for everyone. This lack of individual recognition can unnecessarily restrict a person's independence, employment opportunities, and overall potential.

My son developed **genetic generalised epilepsy** at the age of 19. His seizures are relatively infrequent, occurring approximately once a year when he is unwell or extremely run down. Importantly, he experiences warning signs—known as auras—up to a day before a seizure may occur. These warning signs allow him to recognise when he may be at risk and take precautions.

Today, he manages his condition effectively using a rescue medication. When he notices these warning signs, he takes a single tablet which prevents the seizure from progressing, rests and does not drive until he feels completely recovered.

However, the journey to reach this point was extremely difficult for both him and our entire family.

At age 19, and 18 months into his diesel fitting apprenticeship, he experienced his first seizure after becoming severely dehydrated following a day of water skiing and consuming alcohol. The seizure occurred the following evening. After medical assessment and an EEG, he was prescribed daily medication and immediately lost his driver's licence for six months.

As we live on a farming property in rural Australia, this created major challenges. I was forced to leave our farm so our son could continue his apprenticeship and have transport to and from work. Our family was split apart. My husband remained behind to manage our large grain farming operation and staff alone, while I relocated three hours away to support our son.

What made this situation particularly difficult was that our son was very aware when he was at risk of having a seizure. When he experienced warning signs, he understood that he needed sleep, rest, and recovery. Despite this awareness and responsible behaviour, his licence was removed, leaving him without independence.

Some time later, while on holidays, he experienced another seizure after becoming dehydrated. Once again, he had recognised hours beforehand that something was not right. His licence was again suspended, further removing his independence.

I strongly believe that if our family had not been able to support him with transport and relocation, he may not have been able to complete his apprenticeship. In that situation he may have remained unemployed and potentially struggled with his mental health.

Approximately eighteen months later he experienced a third seizure while unwell with fevers. Again, he experienced warning signs the day before, including auras and absence episodes, indicating that a seizure was likely. As a responsible precaution he rested and did not drive, prioritising both his safety and the safety of others. Despite this responsible behaviour, his licence was once again taken from him.

After this third seizure, I approached his neurologist to ask whether there was anything that could be done when these warning signs appeared to prevent seizures from occurring. It was only at this stage that he was prescribed a **rescue medication**.

Had this medication been offered earlier, it is possible our son may have experienced only one seizure. Our family may not have had to live apart and eventually sell our farm and relocate. We may have avoided the significant emotional and financial strain that followed. Our son may also have maintained his independence and driver's licence during much of this period.

What should have been a **six-month disruption to his life instead became three years of stress, uncertainty, and upheaval for our entire family.**

This experience highlights broader systemic issues within epilepsy care and regulation.

Neurologists must be supported and encouraged to maintain comprehensive knowledge of **all seizure types, treatment options, and rescue medications**. Clearer clinical practice standards should ensure that people living with epilepsy receive treatment plans that consider both seizure control and quality of life.

There must also be greater recognition that epilepsy does not present in the same way for every individual. Some people can reliably identify warning signs and take responsible action to manage risk, including voluntarily ceasing activities such as driving when necessary.

Had our son been offered rescue medication earlier, and had the system recognised his ability to identify warning signs and act responsibly, our family would have been spared considerable hardship.

Instead, the system treated him as a generic case rather than recognising his individual condition and his ability to manage it responsibly.

It is important to acknowledge that epilepsy can be severely debilitating for some people. However, for others, with appropriate treatment options and medical support, it can be managed effectively allowing for a very functional and successful life. Systems must therefore allow for **individual differences rather than applying rigid one-size-fits-all rules.**

Today, our son is a **fully qualified diesel fitter** working for **Hastings Deering**, a company that has shown exceptional understanding and support throughout his journey. His determination and resilience have been

remarkable, particularly within a system that may otherwise have seen him fail without strong family support and advocacy.

Our experience demonstrates that rigid, one-size-fits-all approaches to epilepsy management can unintentionally cause significant harm to individuals and families whose circumstances fall outside standard assumptions. A more flexible, evidence-informed system that recognises patient insight, individual seizure patterns, and modern treatment options would better protect both public safety and the independence of people living with epilepsy.

Policy Recommendations

Based on our experience, the following reforms should be considered:

1. Individualised Epilepsy Management Plans

Patients should receive personalised management plans that recognise the specific nature of their epilepsy, including seizure triggers, warning signs, and personalised response strategies

2. Improved Clinical Awareness of Treatment Options

Neurologists and clinicians should receive ongoing training to ensure awareness of the full range of epilepsy treatments, including rescue medications that may prevent seizures when warning signs occur.

3. Recognition of Patient Insight and Self-Management

Where patients can reliably recognise seizure warning signs, systems should support responsible self-management rather than automatically restricting independence.

4. Review of Driving Regulations

Driving regulations should incorporate mechanisms for **individual medical assessment**, allowing people with well-managed epilepsy to maintain independence while still prioritising public safety.

5. Greater Consideration for Rural and Regional Impacts

Policies should recognise the disproportionate impact of licence restrictions on individuals living in rural and regional communities where access to employment and transport alternatives may be limited.

Conclusion

Epilepsy is not a uniform condition, and policies governing its management should reflect that reality.

With better awareness, more flexible regulatory frameworks, and a greater emphasis on individualised care, people living with epilepsy can maintain independence, pursue careers, and contribute fully to society while still ensuring public safety.

Our family's experience demonstrates both the **unnecessary hardship that rigid systems can create and the positive outcomes that become possible when individuals are supported to manage their condition effectively.**