

# Submission to the Senate Community Affairs References Committee Inquiry into Epilepsy in Australia

Location: Queensland, Australia

Date: March 2026

## 1. Introduction

This submission outlines the lived experience of a person with long-term, partially drug-resistant epilepsy and the profound social, medical, employment, and financial impacts this condition has had over more than two decades.

has lived with epilepsy since childhood and has been medicated for more than 20 years. Despite ongoing treatment, he continues to experience unpredictable seizures that significantly affect his ability to work, maintain independence, and live safely.

spouse and primary carer. The cumulative impact of epilepsy has resulted in substantial financial hardship, loss of employment, and ongoing navigation of complex health and compensation systems.

previously worked in policy and advocacy roles within the Australian arts and media sector and has experience engaging with parliamentary processes. This submission is provided in a personal capacity to outline the lived impacts of epilepsy on individuals and carers.

## 2. Background of the Person Living with Epilepsy

has right temporal lobe epilepsy caused by a benign abnormality in the brain, which specialists have indicated may be a benign tumour or lesion present since childhood.

experiences tonic-clonic seizures and generalised absence seizures, often followed by significant post-seizure (post ictal) confusion and exhaustion.

He has been treated with multiple anti-epileptic medications over more than two decades. His current treatment includes Lamotrigine, however the medication does not fully control his seizures. His condition is therefore considered partially drug-resistant epilepsy.

Despite the long duration and severity of the condition, has not been offered surgical intervention or a clear surgical evaluation pathway despite having a structural brain abnormality and ongoing seizures.

## 3. Seizure Pattern and Neurological Impact

experiences recurrent seizures throughout the year. The frequency is unpredictable and varies depending on stress, fatigue, and health.

Due to the sporadic nature of the condition, it is difficult to reconstruct a complete

seizure timeline spanning decades. However seizures occur multiple times each year and sometimes require emergency medical care.

Over time the repeated seizures have resulted in noticeable neurological impacts including declining memory, cognitive impairment, head trauma from falls, and periods of oxygen deprivation during tonic-clonic seizures.

The cumulative neurological impact of these events has progressively affected cognitive capacity and daily functioning.

#### **4. Serious Injury Resulting from Seizure**

In 2018, while working in a retail sales role at JB Hi-Fi in Hoppers Crossing, Victoria, experienced a seizure and collapsed onto a concrete floor.

was revived in an ambulance by defibrillator. The fall resulted in a fractured jaw requiring surgical repair and the insertion of metal plates and over 6 months of recovery time with a lasting brain injury.

The initial injury required hospital treatment and extended recovery and ultimately resulted in the loss of his employment. Legal action was required to pursue compensation, which resulted in approximately \$20,000 being paid after legal intervention.

Photographic evidence exists documenting the ambulance response and medical assessment of the fractured jaw.

#### **5. Workplace Barriers and Discrimination**

People living with epilepsy often face barriers to employment that are poorly understood.

is physically large (approximately 6'6"), which often leads employers to assume he is healthy and capable without understanding the seriousness of his neurological condition.

As a result, his epilepsy has frequently not been taken seriously until a serious seizure occurs. This has contributed to unsafe workplace environments and employment instability.

#### **6. Recent Workplace Incident and WorkCover Claim**

was most recently employed at Compare the Market Australia between December 2023 and May 2024.

His epilepsy and health circumstances were known to management upon commencing employment in 2023.

During this period experienced a psychological injury and seizure-related incident while travelling to work which led to further health complications.

Following this incident experienced hostility and mistreatment from workplace staff and HR representatives regarding his condition and employment circumstances.

The situation ultimately resulted in the loss of his job and he remains on WorkCover support relating to the workplace-related health impacts.

## 7. Impact on the Primary Carer

Epilepsy also has profound impacts on carers.

is currently full-time carer. Her responsibilities include monitoring seizures, motoring accurate doses of medication, preventing injuries during seizures, coordinating medical care, and supporting recovery after seizure events.

Because is physically large, managing seizures can be physically demanding and potentially dangerous for a carer.

Carers of people with epilepsy often receive limited recognition and support despite the significant demands of the role.

## 8. Financial and Social Impact

Epilepsy has resulted in significant financial instability. has struggled to maintain stable employment due to ongoing seizures and neurological impacts. has also been unable to maintain consistent employment while providing care and managing medical and legal systems related to condition. This has resulted in substantial loss of income and long-term financial pressure.

### 8A. Barriers to Accessing Carer Support

Despite the seriousness of condition, accessing financial support as a carer proved extremely difficult.

was unable to access the Carer Payment for an extended period despite providing substantial care. After extensive discussions with treating doctors, it became clear that access required medical confirmation that was “not likely to improve.”

doctors ultimately confirmed that his condition is not currently likely to improve. This allowed to receive the Centrelink Pension and Carer Payment in February 2025.

While this support is appreciated, the process demonstrates structural barriers where carers may provide full-time care for extended periods yet struggle to access financial support unless a doctor formally states improvement is unlikely.

## 9. Impact on Career and Advocacy Work

previously worked in advocacy and industrial relations roles within the Media Entertainment and Arts Alliance.

During this period was simultaneously managing medical crises, supporting his WorkCover processes, planning a wedding, and navigating significant workplace pressures of her own.

The cumulative demands ultimately made it impossible to continue in her role and she left the position in 2024.

This illustrates how epilepsy can indirectly affect the economic participation and career stability of carers.

## 10. Access to Surgical Assessment for Drug-Resistant Epilepsy

International epilepsy guidelines suggest that individuals with drug-resistant epilepsy and identifiable structural abnormalities should be assessed for potential surgical treatment where appropriate.

has:

- right temporal lobe epilepsy
- a structural brain abnormality
- seizures that continue despite long-term medication

Despite these factors, he has not been offered a clear pathway for surgical evaluation.

For individuals living with drug-resistant epilepsy, surgical assessment can sometimes offer significant improvements in seizure control or quality of life.

The absence of clear referral pathways raises questions about whether people living with long-term epilepsy are consistently being assessed for all available treatment options.

Improving national pathways for epilepsy surgical evaluation would provide patients with greater clarity about their treatment options.

## **11. Risk of Sudden Unexpected Death in Epilepsy (SUDEP)**

A serious issue associated with epilepsy is the risk of Sudden Unexpected Death in Epilepsy (SUDEP).

SUDEP refers to the sudden death of a person with epilepsy where no other cause of death can be identified. It is most commonly associated with uncontrolled tonic-clonic seizures.

For families living with uncontrolled epilepsy, this risk is a constant and serious concern.

experiences tonic-clonic seizures, including during sleep, which can involve:

- breathing irregularities
- oxygen deprivation
- loss of consciousness

For carers, this means constant vigilance and anxiety about the potential life-threatening nature of seizures.

Despite the seriousness of SUDEP, awareness and support for families managing uncontrolled epilepsy remains limited.

Greater public awareness, improved seizure management pathways, and stronger specialist support are critical in reducing this risk.

## **12. Workplace Duty of Care and Epilepsy Awareness**

People living with epilepsy frequently face barriers in the workplace due to limited understanding of the condition and the risks associated with seizures.

Epilepsy can be an invisible disability until a seizure occurs. Many people with epilepsy are capable of working, but they may require reasonable workplace awareness and basic safety planning.

experience demonstrates the importance of appropriate workplace understanding of epilepsy.

In 2018, while working in retail at JB Hi-Fi in Hoppers Crossing, Victoria, experienced a seizure and fell onto a concrete floor. The fall resulted in a fractured jaw that required surgical repair with metal plates.

This incident illustrates the serious physical injuries that can occur when seizures happen unexpectedly in the workplace.

More recently, while employed at Compare the Market Australia, experienced further health complications connected to his epilepsy and his employment circumstances.

These experiences highlight several broader issues affecting people with epilepsy in the workforce.

- Limited Employer Awareness
- Many employers and colleagues have limited knowledge of epilepsy and seizure response.

This lack of awareness can lead to:

- misunderstanding of the condition
- assumptions that individuals are exaggerating symptoms
- delayed or inappropriate responses during a seizure
- inadequate workplace accommodations

Greater education and awareness could significantly improve workplace safety and inclusion.

### **Seizure Safety in Work Environments**

Basic seizure safety planning in workplaces could reduce the risk of serious injuries.

Examples may include:

- ensuring staff understand basic seizure first aid
- identifying potential hazards in work environments
- developing simple response procedures if a seizure occurs
- allowing flexibility when seizures impact attendance or recovery

These measures are often low-cost but can significantly improve safety for workers living with epilepsy.

### **Employment Stability for People with Epilepsy**

People with epilepsy may experience interruptions to employment due to medical episodes, recovery periods, or injury.

Without supportive workplace policies, these interruptions can lead to job loss and long-term financial instability.

Improved employer awareness and clearer guidance around reasonable accommodations could help people with epilepsy remain safely engaged in the workforce where possible.

### **Importance of Education and National Awareness**

Increasing employer awareness of epilepsy would help reduce stigma and improve workplace safety.

National initiatives could include:

- accessible guidance for employers on epilepsy and seizure response
- education about reasonable workplace adjustments
- improved understanding of the realities of living with epilepsy

For many people with epilepsy, meaningful employment contributes significantly to quality of life, financial stability, and independence. Creating safer and more informed workplaces is therefore an important component of broader epilepsy support.

### **13. Systemic Issues Identified**

- Lack of clear pathways for surgical assessment for drug-resistant epilepsy.
- Limited employer awareness and education regarding epilepsy.
- Inadequate recognition and financial support for carers.
- Financial vulnerability caused by employment disruption.
- Insufficient focus on long-term neurological impacts of repeated seizures.

### **14. Recommendations**

1. Establish national standards for epilepsy surgical assessment pathways.
2. Improve workplace education and protections for people living with epilepsy.
3. Expand financial support mechanisms for individuals unable to maintain employment due to epilepsy.
4. Strengthen recognition and support for carers.
5. Increase investment in research into the long-term neurological effects of recurrent seizures.

### **15. Conclusion**

Epilepsy is often invisible until a crisis occurs, yet its impacts are profound and lifelong.

has lived with epilepsy for more than two decades and has experienced serious

injuries, neurological decline, and employment instability as a result of the condition.

At the same time, carers often shoulder significant responsibilities with limited structural support.

We hope this inquiry leads to meaningful reforms that recognise the realities faced by people living with epilepsy and those who care for them.

Queensland, Australia

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