Submission to the Senate Inquiry into Epilepsy Services and Support in Australia

Introduction

My name is and I am the primary carer and partner of a 27-year-old Aboriginal man living with drug-resistant temporal lobe epilepsy. I am writing this submission to share our lived experience navigating diagnosis, treatment, and ongoing care, particularly while living in regional New South Wales.

While this submission reflects experience, it is also shaped by my role as his carer. Our story highlights significant gaps in access to care, support services, and community understanding of epilepsy, particularly for those living outside metropolitan areas.

Barriers to Diagnosis and Access to Appropriate Treatment

was diagnosed with epilepsy in 2021. While his diagnosis itself was not significantly delayed, access to appropriate and specialised care was. At the time, we were living in Tamworth NSW, a regional area with very limited services for complex neurological conditions.

has drug-resistant temporal lobe epilepsy and experiences both focal seizures (lasting 10 seconds to one minute) and generalised tonic-clonic seizures (lasting 40 seconds to two and a half minutes). He also experiences cluster seizures, where he may have between two and four tonic-clonic seizures within a period of 30 minutes to 12 hours. These occur anywhere from fortnightly to every few months.

In Tamworth, there were no specialised epilepsy services available. There was no neurology ward within the local hospital, and no neurologist available for emergency care. This meant that even during severe episodes, was often treated in the emergency department or ambulance bay without access to specialist input or an appropriate environment.

Ambulance response times could take up to an hour. During this time, would often experience multiple seizures before help arrived. post-ictal behaviour is extremely complex and difficult to manage, so not having emergency medication or personnel readily available was hard for us.

Access to a neurologist was extremely limited. care was initially managed via telehealth with a neurologist based in Hobart, with appointments only available approximately every six or so months. This lack of regular, in-person specialist care may have impacted the accuracy of his initial diagnosis and resulted in a period where he was trialled on medications that were not effective for his condition.

The closest location with appropriate specialist services was Newcastle, approximately a 3.5-hour drive from Tamworth. Accessing care required significant travel, time off work, and accommodation costs. Appointments with his neurologist we were seeing via Zoom were approximately $500 per session, in addition to medication costs and travel expenses when going to Newcastle.

As is Aboriginal, we were fortunate to have access to a general practitioner who bulk billed where possible, which assisted with some imaging costs. However, this did not offset the broader financial burden of accessing specialist care.

Ultimately, the lack of accessible, specialised care in regional areas contributed to delays in effective treatment. After relocating to Newcastle and accessing face-to-face care, including specialist epilepsy services and testing, treatment improved significantly, including more appropriate medication management.

Drug-Resistant Epilepsy and Psychosocial and Economic Impacts

epilepsy has had a profound impact on both his life and mine as his carer.

He is unable to drive, which has resulted in a loss of independence and placed full responsibility for transport on me. This has affected both of our employment, as I frequently need to take time off work to support him, attend appointments, and respond to seizures.

The condition has also had a significant impact on mental health. Living with unpredictable seizures has led to anxiety, depression, and a loss of confidence. He has expressed feelings of guilt about the impact his condition has on our relationship.

Socially, his life has changed considerably. He is no longer able to participate in activities such as social drinking or staying out late with friends. His involvement in sport, including football, has also been affected due to both physical risk and stigma.

Physically, is frequently injured as a result of seizures. The constant risk of harm, combined with the unpredictability of his condition, creates an ongoing sense of fear and instability for both of us.

As a couple, we have also had to delay starting a family due to safety concerns and the challenges associated with managing his condition, particularly during post-ictal periods.

Despite these challenges, I remain committed to supporting . However, it is important to recognise the significant and often unacknowledged burden placed on carers, including the difficulty of maintaining employment while providing consistent care.

Barriers to Accessing Support Services, Including the NDIS

We have not applied for the National Disability Insurance Scheme (NDIS), as both and I continue to work and aim to maintain as much normality as possible. However, this highlights a gap in support for individuals who fall outside traditional eligibility expectations but still experience significant disruption to their lives.

We currently access limited support through Centrelink, including carer and mobility allowances. While helpful, these supports do not adequately reflect the true cost and impact of living with epilepsy, particularly where two people are required to do most of their daily life together due to safety concerns.

There is a need for more flexible support systems that recognise individuals who are working but still require substantial assistance due to chronic conditions.

Gaps in Emergency and Support Services

A critical issue we have experienced is the lack of understanding of epilepsy within emergency services, particularly outside of paramedics.

There have been instances where police were required to respond during a seizure-related episode. Due to a lack of training in recognising and managing post-ictal behaviour, was treated as though he was behaving unlawfully rather than experiencing a medical episode. This resulted in him being arrested and placed in handcuffs, hurting himself and police officers, and sustaining significant injuries, despite paramedics attempting to guide the situation.

There is a clear need for improved training for all emergency responders, particularly police, in recognising and appropriately responding to seizures and post-ictal states.

Additionally, there are significant gaps within hospital emergency settings. During one incident, I was not permitted to remain with in the ambulance bay while he was in a post-ictal state. During this time, he discharged himself without capacity to make informed decisions, left the hospital, and subsequently had another seizure outside on concrete. At times, has been placed in an induced coma due to his cluster seizures and post-ictal behaviour - so preventing secondary seizures and ensuring he remains in care for the time needed is crucial for

Following this incident, I raised the issue with hospital management, and I am now permitted to remain with him in all emergency settings and an ‘Alert’ has been placed on his file to accompany this. However, this appears to be an exception rather than standard practice.

Allowing a support person to remain with someone experiencing post-ictal confusion is critical. It helps reduce agitation, improves safety, and can prevent further seizures. There needs to be greater flexibility and formal policy recognising the importance of carers in these situations, and the inability of the person experiencing the seizures to make informed choices when post-ictal.

Community Awareness and Understanding of Epilepsy

There is a significant lack of understanding of epilepsy within the community. Many people assume that all epilepsy involves light sensitivity or tonic-clonic seizures.

In reality, epilepsy presents in many different ways, and much of its impact is not visible. The constant fear, anxiety, and mental health burden associated with the condition are often overlooked.

Improved public education is needed to reduce stigma and increase understanding that epilepsy varies greatly between individuals.

Adequacy of Funding for Research

While I cannot speak in detail to specific funding levels, our experience suggests that continued investment in epilepsy research is critical, particularly in relation to drug-resistant epilepsy.

Access to specialised testing and tailored treatment significantly improved condition once we were able to access appropriate services. Expanding research and ensuring its translation into accessible care is essential, especially in rural, regional and remote areas.

Recommendations

Based on our experience, I recommend the following:

- Increased access to neurologists and specialised epilepsy services in regional and rural areas
- Improved ambulance response times and access to appropriate emergency care in regional locations
- Greater training for police and non-medical emergency responders in recognising and managing seizures and post-ictal behaviour
- Policies within hospitals that allow carers to remain with patients experiencing cognitive impairment or post-ictal states
- More flexible financial support for individuals and carers who continue to work but experience significant disruption due to epilepsy
- Increased public education to improve understanding and reduce stigma
- Continued and expanded funding for epilepsy research, particularly for drug-resistant epilepsy

Conclusion

Our experience demonstrates that where a person lives in Australia can significantly impact the quality of care they receive for epilepsy.

After relocating to Newcastle and accessing specialised services, treatment and quality of life improved. This highlights the disparity between regional and metropolitan care and the importance of equitable access to services.

Epilepsy is a complex and often misunderstood condition that affects not only the individual but also their families and carers. I hope that by sharing our experience, this inquiry can lead to meaningful improvements in access, support, and understanding for others living with epilepsy across Australia.

Thank you for the opportunity to contribute to this inquiry. I would be more than happy to discuss this matter further should you wish.