Submission to the Senate Community Affairs References Committee

Inquiry into Epilepsy in Australia

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1. Introduction

This submission is provided to support the Committee's inquiry into epilepsy in Australia. It draws on lived experience to illustrate the systemic barriers that continue to impede timely diagnosis, equitable access to treatment, financial sustainability, and post-diagnosis support. The issues outlined reflect not only individual circumstances but broader structural shortcomings within Australia's health, disability, and social support systems. Addressing these challenges is essential to improving outcomes for people living with epilepsy, particularly those with complex or drug-resistant presentations.

2. Barriers to Diagnosis and Access to Appropriate Treatment

2.1 Geographic and Systemic Barriers

Early symptoms, including a persistent tremor, were raised with a general practitioner; however, advice discouraging specialist review contributed to a significant delay in diagnosis. This experience reflects systemic failures in primary care, including inconsistent clinical guidance, limited awareness of early seizure presentations, and reluctance to initiate timely referral pathways. Such barriers can prevent early intervention, allowing symptoms to escalate and increasing the risk of severe clinical events.

Following diagnosis, continuity of care was further compromised by the need to transition between multiple neurologists due to the complexity of the condition. These repeated changes disrupted treatment planning and contributed to fragmented care. The lack of coordinated pathways between primary and specialist services demonstrates a broader structural gap that undermines long-term management and patient stability.

2.2 Availability of Medical Practitioners

The uneven distribution of neurologists and epilepsy specialists across Australia significantly limits access to appropriate care. Establishing a stable therapeutic relationship is essential

for effective epilepsy management, yet limited specialist availability, long wait times, and geographic constraints often force patients to travel long distances or navigate multiple health systems.

The submitter has required extensive diagnostic assessment across several major epilepsy centres in Australia and internationally, including Sir Charles Gairdner Hospital, Westmead Hospital, the Alfred Hospital, and the Mayo Clinic in the United States. This reflects the challenges many Australians face in accessing timely, specialised investigations, particularly when local services are unavailable or overburdened.

Early focal seizures at age 12–13 went unrecognised for nearly a decade, with a formal diagnosis only made at age 20 following presentation in status epilepticus. This delay highlights the consequences of inadequate early detection pathways and the need for improved clinical awareness and referral processes.

2.3 Costs and Financial Burden

The financial burden associated with diagnosis, treatment, and ongoing management has been substantial. Travel to the Mayo Clinic in the United States, undertaken in pursuit of advanced diagnostic options, incurred significant personal cost without identifying an operable lesion.

Daily treatment remains expensive, with one essential anti-seizure medication not subsidised under the PBS. These costs are met by family members despite the submitter receiving a Disability Support Pension for mental health conditions closely linked to epilepsy. This reflects systemic gaps in subsidised medication access and the financial vulnerability of individuals reliant on long-term pharmacological treatment.

In 2013, the submitter developed Stevens–Johnson syndrome in response to carbamazepine, requiring urgent specialist intervention and imposing significant physical, emotional, and financial strain on both the submitter and her family. Co-occurring mental health conditions further compound financial pressures, underscoring the need for integrated funding models that recognise the intertwined nature of neurological and psychiatric conditions.

3. Drug-Resistant Epilepsy

3.1 Treatment Complexity

The submitter has trialled numerous anti-seizure medications, many of which were ineffective, poorly tolerated, or associated with serious adverse effects, including Stevens–Johnson syndrome. The need to cycle through multiple medications over many years

highlights the limitations of current treatment options for individuals with complex or drug-resistant epilepsy and the significant clinical and financial burden associated with prolonged treatment trials.

3.2 Psychosocial Impacts on Individuals and Families

Drug-resistant epilepsy imposes substantial psychosocial impacts. Years of uncontrolled seizures, repeated medication failures, and uncertainty surrounding treatment outcomes have caused sustained emotional distress and disruption to daily life. Families experience considerable strain managing unpredictable seizure activity and serious medical events, often without adequate support.

Long-term instability has affected the submitter's independence, education, employment, and financial security. Only now, after many years of instability, is she in a position, albeit a financially constrained one, to pursue university study in occupational therapy in an effort to rebuild her future. These experiences demonstrate the enduring psychosocial burden associated with drug-resistant epilepsy and highlight the need for integrated, long-term psychosocial and vocational supports.

4. Barriers to Accessing Support Services After Diagnosis

4.1 National Disability Insurance Scheme (NDIS)

Accessing appropriate support services has been challenging. The submitter has twice applied for the NDIS and been unsuccessful, despite significant functional impairment arising from drug-resistant epilepsy and associated mental health conditions. The scheme's assessment processes do not adequately recognise fluctuating and episodic conditions, nor do they account for the severe daily side effects of anti-seizure medications, which can impair cognition, mood, energy, and overall functioning.

The absence of funded supports has contributed to financial strain, reduced independence, and limited opportunities for rehabilitation and participation. This experience reflects broader concerns about the adequacy and accessibility of post-diagnosis support services for people living with epilepsy.

5. Recommendations

- Strengthen early detection pathways and improve GP education on seizure recognition
- Expand specialist availability and reduce wait times for neurological assessment

- Improve PBS coverage for anti-seizure medications, including Clobazam
- Ensure NDIS eligibility criteria appropriately recognise fluctuating and episodic conditions
- Enhance access to psychosocial, vocational and long-term support services

6. Conclusion

This submission outlines significant systemic barriers affecting Australians living with epilepsy. Addressing these issues will require coordinated action across government, healthcare, and community sectors to ensure equitable access to diagnosis, treatment, and support. Meaningful reform in these areas has the potential to significantly improve quality of life, reduce long-term health impacts, and promote greater independence and participation for people living with epilepsy.