

Submission to the Senate Committee Inquiry: Epilepsy in Australia

Introduction

I am writing to provide a submission to the Senate Committee regarding epilepsy in Australia. This submission is grounded in my lived experience as a parent, as well as broader concerns about systemic gaps in diagnosis, treatment, support, and community awareness.

My daughter's journey has been complex and challenging. At just three years of age, she suffered a stroke and was later diagnosed with leukaemia. At the age of 12, she developed epilepsy, adding another layer of medical complexity that continues to affect her daily life. She is now 20 years old, and epilepsy remains an ongoing and significant part of her journey.

Through our experience, I have seen firsthand how epilepsy affects not only the individual, but the entire family. It impacts health, independence, education, employment opportunities, and emotional wellbeing. Navigating the healthcare system has often been difficult and, at times, deeply concerning. While attending the public hospital system, it became clear that the level of care was not always adequate to meet her complex needs. The lack of access to specialist expertise and clear guidance in managing her condition as it evolved was particularly apparent.

These gaps created uncertainty, stress, and a sense that we were often left to manage a highly complex condition without the appropriate support or direction. Despite the prevalence of epilepsy, significant barriers remain that prevent timely diagnosis, equitable access to treatment, and appropriate ongoing support. These challenges contribute to increased stress, uncertainty, and financial strain for families like mine.

Barriers to Diagnosis and Access to Treatment

A further concern has been the limited access to broader treatment opportunities, including participation in clinical trials. In our experience, exploring alternative or emerging treatment options was not actively supported. Requests to review or upgrade medications were often discouraged, with clinicians in the Public Hospitals indicating they 'simply did not have the capacity, resources, or pathways to pursue these options.'

The lack of consistent medication management and appropriate follow-up care was deeply concerning, and at times it felt as though my daughter was left to cope with her condition largely on her own. As a result, she experienced significant ongoing impacts, particularly psychosocial: anxiety when travelling on public transport, distress in school, and embarrassment in class settings. These challenges contributed to social withdrawal, reduced confidence, and isolation, affecting both her education and quality of life during critical developmental years.

After extensive research, we eventually sought out a Private neurologist with expertise in adolescent and young adult patients, particularly young women. This specialist provided a clearer diagnosis of my daughter's specific type of epilepsy and reassessed her medication. This change in care has had a significant and positive impact on her quality of life over the past

year. While she still experiences occasional minor seizures, they are far less severe and less frequent than previously endured.

We have also benefited from follow-up appointments via telehealth, which further improved our outlook and provided much-needed reassurance.

I would also like to acknowledge the exceptional support provided by the **Epilepsy Action helpline**. I reached out multiple times for advice, and it consistently gave me clarity, reassurance, and peace of mind. I am deeply grateful for this service, although its limited 9am–5pm availability sometimes required me to wait until the following day to raise urgent concerns.

Equity and Systemic Issues

As both a teacher and a parent of a child with epilepsy—now a young adult—I have seen firsthand the stark differences between the **public and private healthcare systems**. Access to quality healthcare should be universal, not dependent on a family's ability to advocate, navigate complex systems, or afford private care. Our six-year journey could have been significantly shorter with timely access to specialist expertise and consistent support.

My daughter has been deeply impacted by these systemic gaps, yet she has shown remarkable strength and resilience. Families should not have to rely on resilience alone to navigate a system that should support them effectively from the outset.

Conclusion

Neurological disorders such as epilepsy are complex and multi-layered. The current health system does not adequately support a holistic, continuous care journey. Families are often required to stop and start as needs evolve, navigating fragmented services with little coordination or continuity.

This raises an important question—who is truly advocating for the best interests of the child or young person? In our experience, that responsibility has largely fallen on parents and carers, who must manage significant emotional and practical challenges alongside their loved one's condition.

I urge the Committee to strongly review and improve existing processes, including access pathways to specialist care, continuity of treatment, and the availability of medications under the Pharmaceutical Benefits Scheme (PBS). There are effective medications that remain inaccessible or unaffordable for many families, creating inequity in care. Consideration must also be given to age-specific care, particularly for adolescents and young adults, who often fall between paediatric and adult services.

Neurological care must move toward a more integrated, patient-centred approach that supports individuals and families across the full course of their journey—not just at isolated points in time.

I appreciate this opportunity and am grateful for this committee.

Happy to appear in person if the chance arises.

Yours truly
