26th March 2026

Re: Submission to the Epilepsy Parliamentary Inquiry

This submission responds to:

“Barriers to diagnosis and access to appropriate treatment options, including the impact of geographic location, availability of medical practitioners, costs, and cultural and language barriers.”

Introduction

My name is Kristy . I am an Organisational Psychologist based in South Australia, and the mother of a seven-year-old daughter who experienced her first seizure in November 2025.

This submission highlights my perspective on systemic barriers to timely diagnosis and access to appropriate epilepsy care in Australia - where, at multiple points, access depended not on system design, but on persistence, advocacy, and, at times, luck.

Summary of key recommendations

1. Replace outdated referral systems with reliable, trackable digital processes
2. Increase public paediatric MRI imaging capacity and align public and private pathways to ensure timely and equitable access for children.
3. Increase availability of EEG services, including ambulatory and in-home/mobile monitoring options, to support timely and accurate diagnosis.
4. Increase paediatric neurology workforce capacity across both public and private systems, and enable cross-border access to specialist epilepsy services where clinically appropriate, including contingency planning for workforce gaps (e.g. parental leave).
5. Expand telehealth access and establish a coordinated national epilepsy referral pathway, including:
    - Mechanisms to connect patients with available specialist expertise across states and territories, and
    - Improved transparency on specialist availability, areas of expertise, and wait times to support timely access to care.

6. Improve public system responsiveness, introduce means-tested subsidies for essential diagnostic testing and specialist care where delays exceed appropriate timeframes, and better integrate public and private services to support timely access.
7. Introduce clear, accessible pathways to support timely, clinically guided resolution of medical decision-making disputes involving children, ensuring decisions are made in the child’s best interests.

More detail is provided on the following pages.

Lived Experience of Systemic Barriers

1. Delays in Referral and Diagnosis

Following my daughter's initial seizure on 25 November 2025, a referral between hospitals 25kms apart was sent via fax. It was initially lost and ultimately took more than six weeks to be received. Health professionals advised that faxes from this hospital are frequently lost.

In a modern healthcare system, reliance on an unreliable and un-trackable method such as fax is not appropriate - particularly for time-sensitive neurological conditions.

Recommendation (1):
Implement secure, digital referral systems that are instant, trackable, standardised, and eliminate reliance on fax.

2. Barriers to Diagnostic Imaging (MRI)

Access to MRI was significantly constrained.

- Public waitlist exceeded six months and we were referred to the private system.
- One of two private providers (Benson Radiology) had a strict company-wide policy that they would not accept children under eight and referred us back to the public system.
- The only other private imaging company (Dr Jones and Partners) also had a perspective not to accept children under 8, with access only achieved through GP advocacy.

This resulted in us being bounced between services. Had our daughter not been so close to the age cut-off, she would have faced a wait of more than six months for a public MRI to rule out serious causes such as brain tumours or structural abnormalities - timeframes that are not clinically appropriate.

Recommendation (2):
Increase public paediatric MRI imaging capacity and align public and private pathways to ensure timely and equitable access for children.

3. Delays in Diagnostic Testing (EEG)

Access to EEG testing is also constrained.

- Public system wait times can extend to several months for Priority 1 patients.
- There are limited private providers in South Australia
- Access to ambulatory EEGs is extremely limited

In contrast, international models demonstrate what is possible. For example, companies such as Synergy EEG (https://www.synergyeeg.com/) provide in-home video EEG testing, allowing patients to undergo extended monitoring (e.g. 24–72 hours) in their own environment.

Where other countries are bringing diagnostics into the home, Australia remains reliant on limited, hospital-based capacity.

The absence of similar accessible, home-based options in Australia limits the ability to:

- Capture seizure activity in a natural environment
- Expedite diagnosis
- Reduce reliance on hospital-based services

This represents a missed opportunity to leverage innovation in technology to improve access and timeliness of care.

Recommendation (3):
Increase availability of EEG services, including ambulatory and in-home/mobile monitoring options, to support timely and accurate diagnosis.

4. Lack of Timely Access to Specialist Expertise

Access to paediatric neurology in South Australia is currently extremely limited across both public and private systems.

Within the public system, access is significantly constrained. In our experience, it took more than eight weeks (and multiple serious seizures) before we were able to speak with a public paediatric neurologist.

While a diagnosis and medication were provided during that consultation, the appointment was brief and highly time-constrained. There was limited opportunity to ask questions, explore options, or undertake further diagnostic testing prior to commencing medication. We were subsequently required to organise additional investigations independently.

Access to specialist public epilepsy services is also restricted by zoning and catchment rules based on where you live. We identified appropriate within-state (Flinders Public Hospital) and interstate services (e.g. Austin Health in Melbourne) that would have been suitable for our daughter's care, but were unable to access them due to these geographic limitations.

Given delays in the public system, we sought to access private care to improve timeliness and continuity. However, access in the private system was even more limited.

At the time of writing:

- There are no paediatric neurologists in South Australia accepting new private patients
- One paediatric neurologist is returning from maternity leave in April; however, her waitlist already exceeds nine months

As a result, we were required to seek interstate care via telehealth.

This effectively creates a period where no new patients can access timely specialist care within the state, across both public and private systems.

Recommendation (4):
Increase paediatric neurology workforce capacity across both public and private systems, and enable cross-border access to specialist epilepsy services where clinically appropriate, including contingency planning for workforce gaps (e.g. parental leave).

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5. Limited Telehealth and System Coordination

Telehealth access is fragmented, with no centralised referral pathway. Families must independently identify and coordinate care.

Given epilepsy is a condition that can often be assessed and managed using diagnostic data (e.g. EEG, MRI, clinical history), in-person consultation is not always required. Despite this, telehealth access remains limited in Australia and is not available at all within the public system for paediatric neurology in our experience.

This is particularly challenging for regional families. During one hospital visit, we encountered another patient who had travelled more than four hours from Mildura to attend an appointment - highlighting the burden placed on families when local access and telehealth options are limited.

In the context of workforce shortages, there is a clear opportunity to better utilise telehealth to connect patients with available expertise. There is also no visibility within the private system regarding which specialists offer telehealth, are accepting new patients, their areas of expertise, or current wait times.

This lack of transparency delays timely and informed access to care. The current system places the burden on families to navigate fragmented information and coordinate care themselves.

Recommendation (5):
Expand telehealth access and establish a coordinated national epilepsy referral pathway, including:

- Mechanisms to connect patients with available specialist expertise across jurisdictions, and
- Improved transparency on specialist availability, areas of expertise, and wait times to support timely access to care.

6. Cost and Reliance on Private Pathways

Delays and gaps in the public system are effectively shifting the burden of care onto families, who are often required to seek private options to access timely diagnosis and treatment.

In our experience, this has included:

- Private imaging to avoid extended public wait times
- Interstate telehealth consultations to access specialist expertise
- Out-of-pocket costs for diagnostic and monitoring devices (e.g. epihunter, garmin sleep tracker, seizure monitors)

These pathways are not equally accessible to all families and create inequity, where access to timely and appropriate care becomes dependent on financial capacity and the ability to navigate the system.

This also results in a fragmented model of care, where families are coordinating services across public and private providers without clear system support.

Recommendation (6):
Improve public system responsiveness, introduce means-tested subsidies for essential diagnostic testing and specialist care where delays exceed appropriate timeframes, and better integrate public and private services to support timely access.

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7. Lack of Support for Caregiver Decision-Making

Where caregivers disagree on treatment, there is no clear or accessible pathway to resolve decisions in a timely way in the child's best interests.

In our situation, there was disagreement regarding the timing of medication. One caregiver preferred to delay medication until further diagnostic testing was undertaken. However, due to extended delays in accessing those diagnostics, this created significant stress and uncertainty—particularly as our daughter began experiencing nocturnal seizures.

In the absence of a clear system pathway, we relied on our GP to help mediate discussions. This support was informal and dependent on the goodwill of an individual clinician, rather than being part of a structured process.

We also found ourselves making treatment adjustment recommendations to clinicians independently. For example, based on observing that all seizures were occurring at night, we shifted medication timing to be predominantly night-based, despite the original prescription being daytime-focused. These decisions were made through our own research and advocacy, rather than guided through a coordinated care model.

This experience highlights a gap where families are left to navigate complex and high-stakes decisions without sufficient clinical coordination or system support.

This can result in:

- Delays in treatment
- Increased clinical risk
- Significant emotional and psychological strain on families

Recommendation (7):
Introduce clear, accessible pathways to support timely, clinically guided resolution of medical decision-making disputes involving children, ensuring decisions are made in the child's best interests.

Conclusion

From my experience, access to epilepsy care is fragmented, delayed, and often dependent on location and individual advocacy.

Timely diagnosis, access to specialist expertise, and coordinated care are critical. Addressing these systemic barriers would significantly improve outcomes for children and families.

I would welcome the opportunity to provide further information or discuss these insights and recommendations in more detail.