Epilepsy Centre
Senate inquiry into Epilepsy in Australia 2026 Fact Sheet

Introduction

The Parliament of Australia is conducting an inquiry into epilepsy within the country. **This represents a significant opportunity for individuals affected by epilepsy to inform policymakers about their experiences.**

The inquiry seeks input from all persons with direct experience of epilepsy, including those diagnosed with the condition as well as individuals who live with, care for, or support someone with epilepsy.

The Epilepsy Centre and various organisations across Australia will be providing submissions.

Terms of reference

Epilepsy in Australia – Parliament of Australia

Epilepsy in Australia, with particular reference to:

1. barriers to diagnosis and access to appropriate treatment options, including the impact of factors such as:
    1. geographic locations,
    2. availability of medical practitioners, including neurologists,
    3. costs, and
    4. cultural and language barriers;
2. drug-resistant epilepsy and its psychosocial and economic impacts on patients and the community;
3. the level of community awareness and understanding of epilepsy and treatment options;
4. barriers to access support services after diagnosis, including the National Disability and Insurance Scheme;
5. the adequacy of Commonwealth funding for research into epilepsy; and
6. any other related matters.

Key dates

11/3/2026 – Inquiry announced

15/5/2026 – Submission deadline

June 2026 – Hearings

10/9/2026 – Report due

Frequently Asked Questions

Who can make a submission?

Anyone, especially those with personal experience of epilepsy.

Can my submission be private?

Yes. You will need to provide your name and contact details, but you can request confidentiality.

Can I submit online?

Yes. Follow this link Epilepsy in Australia – Parliament of Australia.

What is the deadline for submissions?

15 May 2026.

What will be the outcome?

A detailed report with recommendations to the government will be submitted to the government and organisations like The Epilepsy Centre will advocate for their implementation.

What does the inquiry want to hear about?

- Your own or others' experiences with epilepsy
- Effects on physical and mental health
- Access to diagnosis, treatment, and support
- Community awareness
- Employment and social impacts
- Positive and negative experiences
- Suggestions or recommendations

Where can I get help to prepare my submission?

The parliament website provides guidance Epilepsy in Australia – Parliament of Australia.

The Epilepsy Centre can assist with submission templates, email us for details at - enquiries@epilepsycentre.org.au and thought starter ideas below.

If you require any other assistance in considering and preparing a submission or have any questions, please contact the Epilepsy Centre by email or phone 1300 850 081.

Thought Starter Topics for preparing a submission

If you are currently a person with epilepsy or have been in the past, please consider Topics for People with Epilepsy**.**

If you live with, care for, or interact with someone who has epilepsy, please begin with Topics for Those Who Live With, Care For, or Interact With Someone Diagnosed with Epilepsy.

Topics for People with Epilepsy

- Share the history of your epilepsy—for instance, when you were first diagnosed and any changes you've noticed over time.
- Describe your diagnosis details and the affects you experience.
- Explain how epilepsy affects both your physical and mental health.
- Discuss issues with diagnosis, treatment, and support services, including your experiences with wait times, service availability (especially in regional areas), costs related to specialists, medication, travel, and whether you've accessed support beyond medical treatment (such as through the NDIS).
- Reflect on community awareness in general society, the education system, workplaces, sporting clubs, etc.
- Address social and employment challenges—considering cultural stigma, language barriers, independence, participation, and work opportunities.

Topics for Those Who Live With, Care For, or Interact With Someone Diagnosed with Epilepsy

- The individual's history with epilepsy, such as when they were diagnosed and what has changed since then.
- Detail the symptoms and effects of their epilepsy that you have observed.
- Consider how epilepsy impacts their physical and mental health, and if you are a carer or family member, discuss its impact on your own well-being.
- Talk about any challenges with accessing diagnosis, treatment, and support services, including wait times, availability (particularly in remote areas), costs incurred for specialists, medications, and travel, as well as access to additional supports like the NDIS.
- Discuss public awareness within the community, education systems, workplaces, sports clubs, and more.
- Explore social and employment concerns, such as stigma, language difficulties, reduced independence, social involvement, and job prospects.