

# **Joint Epilepsy Council of Australia**

Australian Chapter of the International Bureau for Epilepsy

The Joint Epilepsy Council of Australia, as the national voice for all Australians living with epilepsy, strongly believes that people living with epilepsy are entitled to the quality of life enjoyed by the majority of Australians.

The number of submissions received within the short timeframe bears testament to the strength of feeling in the community.

People living with epilepsy, their families, carers and support organizations welcome the opportunity to present the lived experience of epilepsy as it exists in Australia today.

10% of Australians will have a seizure during their lifetime (2.1million), while 3–4% will be diagnosed with epilepsy (630,000-840,000).

The aging population coupled with the prevalence of seizure onset in people over 60 means a significant additional challenge lies ahead.

In our recommendations to the Inquiry, JECA has identified six key areas that it believes will produce systemic and lasting change in delivering a 'fair go' for all Australians living with epilepsy.

1. Epilepsy health data.
2. Medical Scientific and psychosocial epilepsy research.
3. National epilepsy awareness campaign.
4. Epilepsy inclusive Workplaces.
5. Universal establishment of epilepsy primary care teams.
6. National support office.

The changes as recommended by JECA will enable all those living and coping with the far-reaching impacts of this 'invisible condition' to participate fully in all aspects of Australian life without the fear of stigma or discrimination

Government support for the non-medical epilepsy sector is inconsistent. Some state and territory governments provide no funding at all. The average funding per annum per person with epilepsy across Australia is \$8.

JECA recognizes the constraints of the current economic climate.

With better utilization of existing government resources, systemic change can occur to improve the quality of life of people living with epilepsy.

There is evidence both from Australia and overseas that the current health paradigm is not working in the best interests of people with epilepsy, and is unnecessarily consuming scarce resources in the accident and emergency, and diagnostic areas of our hospitals.

Australia has islands of world's best practice in epilepsy care and it is now time to develop these into an overall system of epilepsy care accessible to all.

JECA seeks the opportunity to contribute on behalf of people living with epilepsy to the reform process. We seek partnerships to progress harmonization of epilepsy services across the States and Territories.

JECA works collaboratively as a group, shares resources, engages with local and state stakeholders and represents the community of people living with epilepsy. JECA thinks nationally and delivers locally.

In conclusion, on behalf of all epilepsy associations and their clients can I express my heartfelt appreciation for your initiative in establishing this Inquiry.

Your efforts are invaluable in bringing epilepsy out of the shadows.

Graeme Shears  
Chair, Joint Epilepsy Council of Australia