

Inquiry into Epilepsy Parliamentary Friends of Epilepsy

Deadline for Public Submissions 2 October 2009 (Revised)

Information on making a submission

An Inquiry into Epilepsy is being held by The Parliamentary Friends of Epilepsy. The aim is to gain a better understanding of epilepsy and its impact on the Australian community.

There are five Terms of Reference for the Inquiry:

- What is known about the incidence, prevalence, mortality and morbidity of epilepsy in Australia;
- Gaps in our understanding regarding the incidence, prevalence, mortality and morbidity of epilepsy in Australia;
- The barriers to social and economic participation for people living with epilepsy, including education, employment and transport;
- The adequacy of current models of medical care; and
- Practical measures which will better support people living with epilepsy.

Submissions are invited from people living with epilepsy, their families and carers, and people or organisations that are supporting, providing services, or interested in improving the lives of people living with epilepsy.

Your personal experiences and suggestions for improvements in the health, disability or social services systems will help the Inquiry to understand what it is really like to live with epilepsy and the practical services needed to ensure that people living with epilepsy have equal opportunities to participate in community life and the support they need.

The Parliamentary Friends of Epilepsy is a group formed by the Joint Epilepsy Council of Australia (JECA) within the federal parliament.

More information and assistance

If you need help with your submission, please call the Epilepsy Foundation of Victoria 03 9805 9111 or Epilepsy Australia on 02 9674 9966.

Where to send your submission

By post:

Inquiry by Parliamentary Friends of Epilepsy
Jill Hall MP
Federal Member for Shortland
PO Box 499
Belmont NSW 2280

Or by email:

mark.raper@aph.gov.au

How to make a submission

You may make a submission about your personal experiences with epilepsy, your views or your suggestions. Your submission may be in a letter, a short document or a longer paper.

As well as including as much of your own story as you feel comfortable telling, you may also say what you think government should do to improve the quality of life for people living with epilepsy.

It is also important to make sure that your submission is within the scope of the Inquiry, so try not to stray too far from the Terms of Reference. The Terms of Reference are broad enough to allow you to cover a wide range of points and recommendations. Your submission may contain facts, opinions, arguments or recommendations. It may cover all the points in the Terms of Reference or only some of them, depending on what interests you.

The following questions are a guide when writing your submission:

- What is it like living with epilepsy or having a child or partner who has epilepsy and what impact does it have on the family?
- How difficult is it, or was it, to get appropriate treatment?
- What barriers do you face as a person living with epilepsy? What practical things would assist you to overcome these?
- What support and assistance do people living with epilepsy need to complete their education?
- What support and assistance do people living with epilepsy need to get a job and then stay in the workforce?
- Have you experienced discrimination because of your epilepsy?
- What are the important things you need from the health, education and disability support system? How could the system better serve your family?
- How do you see the future for yourself and your family?
- What government help or support do you expect in the future?
- What innovative ideas do you have to improve the quality of life for people living with epilepsy?

The following has been taken from the Fact Sheet 'How to make a Submission to a Parliamentary Inquiry' on the House of Representatives website:

<http://www.aph.gov.au/house/committee/documnts/howsub.htm>

- A submission may be as **short or as long** as you like.
- You **do not have to follow a particular format** for your submission. However, to make your submission easy to follow, we suggest writing it in the order of the Terms of Reference.
- You may attach other documents to support your submission.
- If the submission is longer than a few pages, please include a summary at the start.
- Submissions may be in hard copy, either **hand-written** or **printed**, or can be made by **email**.
- If you are hand-writing your submission, but please make sure it is written clearly so people can read it, and that it is suitable for photocopying (preferably use a **black pen**, not blue).
- **Emailed** submissions must include your **name, telephone number and postal address** for verification.
- It is helpful if each hard copy submission is sent with an electronic version on disk or CD-ROM, preferably in Microsoft Word® or Portable Document Format (PDF). This helps with publishing submissions on the Parliament's website.
- Make sure you sign your submission.
- Your submission must include:
 - (1) **Your name**
 - (2) **A postal address for correspondence**
 - (3) **A contact telephone number**
 - (4) Your position (for example, facilitator, president) if you are making a submission on behalf of an organisation or epilepsy support group.

Confidentiality

If you wish, you can ask that your submission be kept confidential and not published, or you can ask that it be published as a confidential submission without your personal details. The Inquiry will consider your request for confidentiality but reserves the right to publish your submission.

More information and assistance

If you need help with your submission, please call the Epilepsy Foundation of Victoria 03 9805 9111 or Epilepsy Australia on 02 9674 9966.

Where to send your submission

By post:

Inquiry by Parliamentary Friends of Epilepsy
Jill Hall MP
Federal Member for Shortland
PO Box 499
Belmont NSW 2280

Or by email:

mark.raper@aph.gov.au