



Parliamentary Friends of Epilepsy

**INFORMAL INQUIRY INTO
THE IMPACT OF EPILEPSY IN AUSTRALIA**

PARLIAMENT HOUSE CANBERRA 30 NOVEMBER 2009



Epilepsy is one of the most misunderstood, and therefore least understood, conditions of our time. It does indeed 'stay in the shadows' of our community.

Some of the earliest writings on this disease reveal that it was once known as the 'Holy Sickness' and notably studied by the Greek physician Hippocrates. Recent translations of a Babylonian tablet dating from about 500 BC have revealed even earlier descriptions of epilepsy.

St Mark in Chapter 9, Verses 17-18, indicated an incident of epilepsy; "he has an evil spirit in him and can not talk. Whenever the spirit attacks him, it throws him to the ground, and he foams at the mouth, grits his teeth and becomes stiff all over." Today the condition would most likely be diagnosed as a grand-mal seizure, but at the time, traditional healers would most likely surmise that there had been an act committed against God, along with the presence of demons, that caused the horrific episode.

Although times have changed and diagnosis and treatments improved, sadly, the wider public still has little knowledge of the condition.

It is time that all sectors of the community, from politicians to shopkeepers, neighbours, employers and particularly those in the public sector charged with assisting people with disabilities, unite to ensure that awareness raising and education of this disabling condition becomes a social priority.



PARLIAMENTARY FRIENDS OF EPILEPSY: THE IMPACT OF EPILEPSY IN AUSTRALIA IN 2009

Parliamentary Members

Jill Hall MP, Senator Gary Humphries, Damian Hale MP, Mark Coulton MP

BACKGROUND

The Parliamentary Friends of Epilepsy group was formed in 2008 following lobbying by members of JECA.

Subsequently, the Parliamentary members group resolved to further the support provided to this large, but not widely known or accepted condition, by calling for submissions from interested parties, particularly patients and carers. The submissions were sought with a view to holding an informal hearing to gain views of patients, carers and professionals involved with Epilepsy.

Some comments on those submissions are included in this report.

THE HEARING

The informal hearing was held in Parliament House Canberra on Friday 30 November 2009, commencing at 9.30 am. The Parliamentary members welcomed participants and expressed thanks for their co-operation in making themselves available at short notice.

All participants expressed their thanks for holding the inquiry, as it was the first time the condition was having a national voice, the opportunity to come out of the shadows, and to raise awareness of the condition for politicians and the general public.

Two main sessions were held, one in the morning for the professional and organisation support groups, and an afternoon 'round table' session to provide an opportunity for persons with epilepsy and their carers, to provide input to the discussion.

RECOMMENDATIONS:

1. That the Government undertake a comprehensive education/awareness raising program on epilepsy for all sectors of the community, including government agencies such as Centrelink.
2. That Government departments, especially Centrelink, be required to review their policies to include a new definition of disability that includes epilepsy, provide better access to services and benefits for those affected by epilepsy and one application to cover access to services in all government agencies.
3. That positive employment and support services in government agencies be developed to recognise the needs, abilities and contributions of those with epilepsy, thereby removing barriers to employment for this group.
4. That additional questions regarding epilepsy be included in the National Health Survey to provide accurate data on incidence, treatment etc.
5. That greater emphasis be placed on research, data collection and standardisation of data regarding epilepsy.
6. That adequate government funding be made available to the various Epilepsy support groups and that they be encouraged to work together to ensure they attract maximum funding.
7. That initial training and ongoing medical education for GP's and nurses be reviewed and improved to ensure training is adequate in quantity, is of a high quality and is current in relation to diagnosis, treatments and impact in individual lives. Ongoing education and training to be provided through the Urban Division of General Practitioners and existing Nurse Education Networks..
8. That given the unique transport difficulties, including public transport, experienced by those with epilepsy resulting from the nature of sudden, episodic seizures and the aftermath; State Governments be encouraged to review taxi voucher eligibility criteria to better accommodate the needs of those with epilepsy.
9. That the Parliamentary Friends of Epilepsy support recommendation No 6 of the 'Who Cares' Report:
"Recommendation 6
That the Australian Government consider consolidating portfolio responsibility for people with disabilities, people with mental illness, the frail aged and their carers into a single Australian Government department."
10. The Parliamentary Friends of Epilepsy believe that the process for approving new treatments and technologies for epilepsy needs to be responsive to the latest scientific developments.
11. That investigation into ways to improve access to services, doctors and specialists for rural and regional areas be undertaken.
12. That the Federal Government support a system of Epilepsy Ambassadors across Australia.
13. That the Federal Government write to the States and Territories to ensure that epilepsy is covered by the criteria for disability in all areas.