

Joint Epilepsy Council of Australia

Australian Chapter of the International Bureau for Epilepsy

2 October 2009

Ms Jill Hall MP
Member for Shortland
PO Box 499
Belmont NSW 2280

Email: Mark.Raper@aph.gov.au

Dear Ms Hall

Parliamentary Friends of Epilepsy: **Inquiry into the Impact of Epilepsy in Australia today.**

The Joint Epilepsy Council of Australia (JECA) welcomes the Parliamentary Friends of Epilepsy *Inquiry into the Impact of Epilepsy in Australia today.*

This is the first time epilepsy has received the attention of our Federal Members and Senators and JECA commends the initiative taken by our Parliamentary Friends of Epilepsy.

Our constituency applauds the Parliamentary Friends of Epilepsy for providing this forum for people living with epilepsy, their families, carers and support organisations to present the experience of epilepsy as it exists in Australia today.

We hope that the submissions to the Inquiry form a compelling understanding of the realities of living with epilepsy in Australia today, and that Members and Senators are rightly moved to advocate within the Parliament for systemic and sustainable change.

Such changes as recommended by JECA will enable all those living with 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.

JECA is pleased to formally respond to each of the Terms of Reference of the Inquiry in the following pages and in conclusion makes a series of recommendations to the Inquiry, supported by the accompanying attachments.

Yours sincerely



Graeme Shears
Chair, Joint Epilepsy Council of Australia

Attachment A: A Fair Go for People Living with Epilepsy: Report to the Parliamentary Friends of Epilepsy (updated), October 2009.

Attachment B: Internationally recognised national bodies – Joint Epilepsy Council of Australia; Epilepsy Society of Australia.

1. What is known about the incidence, prevalence, mortality and morbidity of Epilepsy in Australia

Little is known about the epidemiology of epilepsy in Australia so we must rely on international studies when assessing burden of disease and injury in epilepsy¹, when allocating scarce funds and resources, and when planning delivery of services.

From international data the prevalence of epilepsy is generally taken as between 4 and 10 cases per 1000 persons, and the overall incidence as about 50 cases per 100 000 persons.² Cumulative incidence or the number of people who will have epilepsy in their lifetime is estimated to be between 3–4 per cent of the population.³

Extrapolation of this data to the Australian population (22 million) suggests that the total number of people with epilepsy in Australia today falls somewhere between 88,000 and 220,000, with some 660,000–880,000 Australians having epilepsy in their lifetime. Epilepsy does not happen in isolation, it is a 'family condition' that impacts on all members, and it is estimated that those affected today number between 352,000 and 880,000, with some 2.6 million–3.5 million Australians affected over their lifetime. This broad range poses obvious challenges for epilepsy organisations trying to meet the unmet needs of this population today, and planning to meet their needs in the future.

It is generally acknowledged that epilepsy carries an excess mortality of 2–3 times that of the general population; sudden unexpected death in epilepsy, accidental death such as drowning or from injury, and suicide. Approximately 300 epilepsy-related deaths occur in Australia each year with approximately 150 of these deaths being attributed to sudden unexpected death in epilepsy (SUDEP).⁴ The risk of suicide is increased in most populations of people with epilepsy⁵ while sudden epileptic seizures can cause accidents or injuries that may be fatal, including drowning.⁶ The lack of a uniform approach across Australia in the documentation of the circumstances surrounding an epilepsy-related death and the certification of sudden unexpected death in epilepsy (SUDEP) suggests that these figures are understated.

Morbidity in epilepsy reveals that people with epilepsy suffer from physical and psychiatric effects of their seizure disorder, with depression and anxiety disorders rating highest among people with epilepsy.⁷

¹ Begg, S., Vos, T., Barker, B., Stevenson, C., Stanley, L., & Lopez, A. The burden of disease & injury in Australia. Canberra: AIHW, 2007.

² Forsgren, L., Beghi, E., Oun, A., & Sillanpaa, M. (2005). The epidemiology of epilepsy in Europe - a systematic review. *European Journal of Neurology*, 12(4), 245-253.

³ Hauser, W. A., Annegers, J. F., & Rocca, W. A. (1996). Descriptive epidemiology of epilepsy: Contributions of population-based studies from Rochester, Minnesota. *Mayo Clinic Proceedings*, 71(6), 576-586.

⁴ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p.25

⁵ Bell, G.S., Gaitatzis, A., Bell, C.L., Johnson, A.L., & Sander, J.W. Suicide in people with epilepsy: How great is the risk? *Epilepsia*, 50(8), 1933-1942.

⁶ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p. 26

⁷ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p.21

2. Gaps in our understanding regarding the incidence, prevalence, mortality and morbidity of Epilepsy in Australia

Epilepsy can be difficult to diagnose. It is often confused with other conditions and the lack of a clear beginning or end can complicate epidemiological estimations. Reluctance to disclose the condition also limits research. While epilepsy may diminish in some individuals, the psychosocial effect of epilepsy can endure beyond the active phase of the condition. Effects on education, self esteem, or employment opportunities may be carried for many years.⁸

In Australia epilepsy generally remains unidentified or poorly identified in national health data collections with Australian data sources quoting international study figures when discussing burden of disease and injury in relation to epilepsy.

There is little on the epidemiology of epilepsy in Australia: the foundation work of the Tasmanian Epilepsy Register by D'Souza identified areas for further study⁹, while the SEISMIC Study currently undertaken by The George Institute Research has reported pilot study results¹⁰. Commonwealth investment is necessary to foster ongoing and sustainable epidemiological research.

Our understanding of the epidemiology of epilepsy in Australia could be greatly improved by the systematic collection and analysis of relevant epilepsy data through government agencies. This could be achieved by:

- ensuring the National Health Survey gathers information about epilepsy and seizure prevalence;
- supporting the inclusion of questions relating to attitudes towards epilepsy in the Australia Survey of Social Attitudes; and
- making the study of epilepsy an area of targeted assistance by the National Health and Medical Research Council
- supporting research into the morbidity of epilepsy and its impact on quality of life;
- ensuring that a national uniform approach is adopted in the certification of epilepsy-related death, especially sudden unexpected death in epilepsy (SUDEP).

⁸ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p.7

⁹ D'Souza WJ, Fryer JL, Quinn SJ, Taylor BV, Ficker DM, O'Brien TJ, et al. The Tasmanian Epilepsy Register – a community-based cohort. Background and methodology for patient recruitment from the Australian national prescription database. *Neuroepidemiology* 2007;29(3-4):255-263.

¹⁰ Martiniuk, A., Anderson, C., Somerville, E., Hackett, M., Glozier, N., & Bleasel, A. Designing research in epilepsy to ensure policy change: Sydney epilepsy incidence study to measure illness consequences (SEISMIC). Conference paper, 28th International Epilepsy Congress, Budapest, 2009.

3. The barriers to social and economic participation for people living with epilepsy, including education, employment, and transport.

"The social consequences of epilepsy are often more difficult to overcome than the seizures themselves."
World Health Organization

Stigma:

Superstition and stigma have surrounded people with epilepsy for thousands of years, creating formal and informal barriers to participation in community life, many of which still exist. Seizures can challenge the norms of social behaviour; they are unpredictable, and in some cases involve unusual physical actions and loss of control over bodily functions. Due to the lack of community education and understanding or erroneous perceptions of epilepsy many people living with epilepsy are discriminated against or stigmatised. In Australia, the Human Rights Commission reported that epilepsy is often experienced as a severe social handicap due to the stigma attached to it.¹¹

A recent survey conducted by JECA found that 53% of respondents have experienced discrimination at some point and of those, 51% have experienced discrimination in the last 12 months. The most common place for discrimination is the workplace, followed closely by educational institutions.¹²

Education:

Epilepsy is a chronic disorder that significantly affects education outcomes. Barriers to academic achievement include psychosocial, medication-related, and epilepsy-related factors associated with learning disabilities, resulting in lower retention rates. Academic under-achievement can also be related to teacher knowledge of epilepsy and its management in the classroom, teacher attitude towards students with epilepsy, teacher expectation.¹³

The stigma associated with epilepsy can make it difficult for students to feel included with their peers. Even in the early years, children with epilepsy start to experience the barriers brought about by their condition when they can't attend school camps, restricted participation in school swimming carnivals, sporting events and school excursions.

Employment:

People with epilepsy have been shown to be up to three times more likely to be at risk of unemployment and subject to underemployment, relative to their levels of skill and qualifications, than people with other chronic illnesses. Underemployment contributes very significantly to the economic burden of epilepsy. For many people with epilepsy, employment is a major quality of life issue that impacts heavily on their financial status and psychological wellbeing.

Stigmatisation in the workforce is common and can affect employment, career advancement, and personal and professional relationships with colleagues.¹⁴

Given the high level of unemployment and intermittent nature of seizure control the number of people with epilepsy engaged in the full time workforce is low. Subsequently the number of people receiving government support such as the Disability Support Pension is likely to be higher. Government agencies such as CRS Australia, Centrelink, Job Network Providers and other vocational organisations need to be fully equipped to understand epilepsy, its impact on the person, and the person's individual needs, in order to effectively assist the person with epilepsy to gain employment.

¹¹ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. pp.18–19.

¹² Joint Epilepsy Council of Australia. Life with epilepsy report. Canberra: JECA, 2007

¹³ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p.26.

¹⁴ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p.27.

Transport:

Transport and travel is something that most people take for granted, but it is clearly very difficult for many people living with epilepsy to get from place to place.

In a recent survey, only one third of people living with epilepsy drive their own car and of this group, over half have had their driving license suspended at some time. People with epilepsy spend an average of \$37.42 a week on transport. The cost of taxi transport limits travel for over half of those with epilepsy, with 23% unable to afford travel by taxi. This is doubtless due to a number of factors from inability of many people with epilepsy to work full time and their consequently lower incomes, the generally heightened costs of living with chronic illness, fear of having a seizure while on public transport, and the inadequacy (as well as the national inconsistency) in travel assistance for people with epilepsy.^{15,16}

Almost all people diagnosed with epilepsy who hold a driving license, will have their license suspended for a certain period time, the minimum being three months, until they can show seizure control. This can result in restricted or loss of employment, social isolation and increased dependence on family, friends, public transport, and taxis for mobility.

For those whose epilepsy is not controlled, driving will never be an option, and they will always have to rely on other forms of transport to get around. However for those who do not qualify for a license, are not considered severe enough to be able to participate in State or Territory taxi transport subsidy schemes, and do not have family or carers to rely on for transport, the fear of having a seizure on public transport can prove debilitating and isolating. The lack of public transport in rural and remote areas can be isolating adding to feelings of social exclusion.

¹⁵ Joint Epilepsy Council of Australia. Life with epilepsy report. Canberra: JECA, 2007

¹⁶ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p.28.

4. The adequacy of current models of medical care

'No seizures, no side effects' – US National Centre for Chronic Disease Prevention and Health Promotion.

As a community based agency JECA recognises that research indicates Quality of Life (QoL) in epilepsy is strongly related to seizure frequency and therefore the organisation has a fundamental responsibility to advocate strongly for gold standard medical service, which provides the best opportunity for complete seizure control.

People with epilepsy often appear to be invisible in health policy¹⁷ and the opportunity now arises with the recently published Final Report of the National Health and Hospitals Reform Commission – *A Healthier Future For All Australians: Final Report*, for epilepsy to be included in these major health reforms currently being considered by the government.

Mapped against this Report, JECA considers the most important health issues in epilepsy to be:

- The prevalence of epilepsy among Aboriginal and Torres Strait Islander peoples.¹⁸
- Access to services for people living with epilepsy in remote and rural areas.
- Timely access to quality care in public hospitals including improved access to specialist care.
- Timely access to investigative procedures such as electroencephalographic (EEG) recordings, magnetic resonance imaging (MRI), video-EEG and positron emission tomography (PET) for adults and especially children.
- Immediate inclusion in the National Chronic Disease strategy. Whilst epilepsy may not fit easily into a generic chronic disease management program (CDM), issues such as better understanding one's condition, improved self-efficacy and enhanced doctor-patient communication are all features of chronic disease self management, that would benefit people with epilepsy.¹⁹
- Resourcing primary care practitioners with referral pathways to specialist epilepsy management, especially in the area of diagnosis and initial treatment, and referral pathways to professional non-medical community services.
- Integrating acute care and community epilepsy services thus strengthening primary health care services²⁰ by focusing on proper diagnosis, treatment and patient adherence thus minimising avoidable hospitalisations.²¹
- Strengthening consumer engagement and voice through promoting an understanding of and positive attitudes to epilepsy through the National Curriculum for schools using JECA's epilepsy-friendly school program as a model,²² and empowering consumers to make fully informed decisions about their health management: annual review, improved seizure control, new medications, generic medications, fewer side effects, and surgery options.

Public health policy in Australia does not define best practice frameworks for epilepsy care. Initiatives such as First Seizure Clinics, focusing specifically on new onset seizures, have been instigated in

¹⁷ Walker C. Epilepsy in Australian policy: A review of Australian health and social welfare policies which recognise and redress the impact on individuals, their families and the Australian community. Camberwell: Epilepsy Foundation of Victoria, 2008.

¹⁸ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p.22.

¹⁹ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p.17.

²⁰ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p.14.

²¹ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p.15.

²² See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p.28.

some states but these have been initiated by practitioners working in strong epilepsy centres rather than as part of national health care policy.²³

As with all people living with chronic conditions, people with epilepsy are disadvantaged by the divisions that exist among all the essential services which vary in quality from region to region and state to state. These services range across the spectrum of health, education, community, social and disability sectors.

²³ See Attachment A. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p.15.

5. Practical measures that will better support people living with epilepsy

While epilepsy is a lower prevalence condition, the psychosocial, educational and economic impacts outweigh the clinical symptoms, creating particular challenges for the delivery of social and health services.

In building on principles of social inclusion, the attached Report outlines creative strategies across a range of issues that will ensure that people living with epilepsy receive equitable care and access to services.

Recommendations:

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

1. An improved understanding of the impact **epilepsy** has on Australia, its people and its economy **by ensuring the National Health Survey gathers information about epilepsy and seizure prevalence, supporting the inclusion of questions relating to attitudes towards epilepsy in the Australia Survey of Social Attitudes, and supporting more detailed applied social research into the morbidity of epilepsy and its impact on quality of life.**
2. An appropriate proportion of our world-class research effort targeted to the better diagnosis and treatment of **epilepsy by making the study of epilepsy an area of targeted assistance by the National Health and Medical Research Council.**
3. Communities that are increasingly aware of **epilepsy**; what it is, how to manage it, so that people with epilepsy can live, work and be educated without stigma and be active community participants **through a targeted national epilepsy awareness campaign.**
4. Workplaces that are informed, free of stigma, and support those with **epilepsy** to remain in employment **through support to develop and undertake workplace awareness programs.**
5. Health services that reflect world's best practice in promoting the right care by the right health professional in the treatment and management of **epilepsy by ensuring that primary care teams are funded to support the multidisciplinary needs of people with epilepsy.**
6. Support people with **epilepsy** and their carers so that they are assisted in their pursuit to manage their condition and actively participate in the community **by supporting the establishment of a national epilepsy support office, to represent the needs of people with epilepsy and their carers, and to work with National and State bodies.**