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Australian Chapter of the International Bureau for Epilepsy

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Submission from the Joint Epilepsy Council of Australia Inquiry into Suicide in Australia

Suicide and epilepsy

People with epilepsy are more likely to die prematurely and suicide is an all too common cause of death.

A recent submission by the Joint Epilepsy Council of Australia to the Parliamentary Friends of Epilepsy “Inquiry into the Impact of Epilepsy in Australia today” comprehensively details the issues facing people living with epilepsy, and is attached for further information (Appendix 1).

Epilepsy

Epilepsy is the world’s most common serious disorder of the brain according to the World Health Organizationⁱ. WHO reports that the burden of epilepsy accounts for 0.5% of the global burden of disease. This can be compared with multiple sclerosis at 0.1% or breast cancer at 0.4%, or diabetes at 1.3%.ⁱⁱ

A seizure is a disturbance of movement, feeling, thought, or consciousness occasioned by sudden, inappropriate and excessive electrical discharges in the brain. The tendency to have recurrent seizures will usually attract a diagnosis of epilepsy. Epilepsy doesn’t discriminate – it can happen to anyone of any ability, background, or age (although it is more common in children and those over 65 years of age). Medication is of assistance in controlling seizures in about 70% of people with epilepsy.

The impact of epilepsy

Epilepsy has the potential to have a profound effect on every aspect of someone’s life. The seizures themselves may cause injury and embarrassment. The person may lose their independence – for example losing their driver’s licence, and/or employment, accompanied by a loss of financial independence. Sadly people living with epilepsy often find they become socially isolated – relationships with significant others may deteriorate, their friends reject them, usually due to fear. In the wider community this fear may manifest as discrimination.

There are medical tests and trips to medical specialists who may be hundreds, even thousands of kilometres away. Medication is potentially another source of stress with unwanted side effects including fatigue and cognitive problems. Psychosocial adjustment is not determined by seizure frequency and/or severity. One may have severe epilepsy and cope quite well. Others have less severe epilepsy but become profoundly psychosocially impaired with loss of self esteem and confidence, anxiety, and a sense of diminished control over their life ⁱⁱⁱ. It is true that people with other chronic illnesses may also experience psychological disorders, however a community based study found that people with epilepsy had higher depression scores than people with asthma or in a control group.^{iv}

Psychological effects

There are many types of seizures and individuals vary considerably in regards to the way seizures manifest and impact. Some may experience psychological effects with their seizures – for example hallucinations, aggression, extreme fear or sadness.

It is well documented in the medical literature that people with epilepsy experience much higher rates of psychological disorders than the general community. The following table from a presentation by Salzberg (2008)^v clearly demonstrates the incidence of common psychological disorders in epilepsy.

Psychiatric Disorder	Epilepsy Patients	General Population
Depression	30-50%	5-17%
Generalised Anxiety Disorder	15-25%	5-7%
Panic Disorder	5-21%	0.5-3%
ADHD	12-37%	4-12%
Psychosis	2-9%	1%

Ettinger & Kanner. Psychiatric Issues in Epilepsy. 2nd Edition LWW 2007^{vi}

Salzberg suggests 4 possibilities for the link between epilepsy and depression:

1. Epilepsy causes depression because it's an understandable reaction and epilepsy has an affect on the brain (underlying disease, seizures, and medication)
2. Stress hormones associated with depression have an effect on the brain, triggering seizures. One hypothesis is that depression is a risk factor for epilepsy onset.
3. There may be shared causation for epilepsy and depression.
4. All of the above.

There is still much to be learnt about the interactions between neurobiological, iatrogenic and psychosocial factors ^{vii}.

A history of depression is associated with a 4- to 6- fold greater risk of developing epilepsy. Kanner (2003) says that the clinical presentation of depressive disorders in epilepsy can be identical to that of nonepileptic patients, however in a significant percentage of cases the clinical features of epilepsy fail to meet any of the DSM-IV Axis I categories.

In spite of the comparatively high incidence of psychiatric disorders in epilepsy, unfortunately they are under recognized, under diagnosed and under treated. Both the clinician and patient may have a role to play in minimising the significance of the symptoms, because they

consider depression and anxiety to be a normal way of responding to the condition^{viii}, or a belief that antidepressants are ineffective or will exacerbate seizures^{ix}.

Epilepsy-related death

A recent report into avoidable mortality in Victoria between 1997 and 2003 found that epilepsy was in the top five causes of death in the 5–29 year age group. It is interesting to note that in the 15–29 year age group the top four causes were all accident-related or due to self-harm. Epilepsy was the only chronic condition listed in the top five.^x

There are approximately 300 epilepsy-related deaths in Australia per annum.^{xi} More than half of these are due to SUDEP (sudden unexplained death in epilepsy).

The risk of suicide in people with epilepsy has been estimated to be 10 times higher than in the general population.^{xii}

Recommended strategies

- Improve the accuracy and specificity in recording epilepsy-related death, including suicide. Being mindful of the family's need for timely closure would also be of assistance.
- Emergency services staff need to know basic information about epilepsy – how to identify seizures, and how to respond appropriately. In the past inappropriate responses have greatly exacerbated the distressed state of the person with epilepsy.
- JECA applauds the public awareness campaigns undertaken by the government and depression/mental health organisations, however there has been little regard for the needs of people with epilepsy in these programs. We would encourage inservice training about epilepsy for front line workers and those involved in the development of information campaigns.
- Epilepsy support organisations have a great deal of expertise about epilepsy. Funding support for JECA to develop specially tailored programs in collaboration with leading mental health organisations would ensure targeted and effective information and psychosocial support programs for the common psychological disorders. Early intervention will save lives.
- Allocation of mental health research funding to research psychological disorders in epilepsy.
- Implementation of the strategies discussed in the submission for the Parliamentary Friends of Epilepsy inquiry to enhance quality of life generally for people with epilepsy will assist in ameliorating the stresses and challenges that may give rise to psychological disorders and ultimately suicide.

Yours sincerely



Graeme Shears,
Chair, Joint Epilepsy Council of Australia

Attachment 1: A Fair Go for People Living with Epilepsy: Report to the Parliamentary Friends of Epilepsy

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A Fair Go for People Living with Epilepsy in Australia

**A Submission to the Parliamentary Friends of Epilepsy
Inquiry into the impact of epilepsy in Australia today**

2 October 2009

**Joint Epilepsy
Council of Australia**

Australian Chapter of the International Bureau for Epilepsy



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Executive Summary

A Call for a National Approach

The Joint Epilepsy Council of Australia (JECA)^a welcomes the opportunity to discuss with government, areas in which we can work together to improve service delivery and quality of life for people living with epilepsy. The thrust of our approach requires national leadership from government, the medical and the non-medical epilepsy movements.

The time has come, while working locally, to also think nationally in order to develop sustainable capacity for epilepsy care and support throughout Australia.

Epilepsy is a highly complex condition in its causes, presentation, and treatment, and requires both medical and non-medical management.

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. Building on principles of social inclusion, JECA aims to foster creative strategies to ensure that those affected receive equitable care and access to services nationwide.

This Inquiry on the impact of epilepsy in Australia will, for the first time, gather valuable information on what is known of the incidence, prevalence, mortality and morbidity of epilepsy in Australia and identify the gaps that exist in Australian epidemiological data; the barriers that exclude people living with epilepsy from social and economic participation; whether current models of medical care for people living with epilepsy are adequate; and practical measures that people living with epilepsy and those working in the epilepsy field believe would better support people living with epilepsy. JECA applauds and supports this initiative.

The Current Situation

JECA accepts that for too long internal divisions within the Australian epilepsy movement have stymied opportunities for reform. There have also been significant and profound differences in the level of support provided in each State and Territory. Over time each State and Territory non-medical associations have endeavoured to create positive differences for people living with epilepsy but clearly some strategies have failed. New approaches need to be developed and adopted.

The formation of JECA in 2003 created a new level of cooperative action amongst the non-medical epilepsy movement and the time is right to embed this and achieve other changes for the people we represent – people with epilepsy, their families and carers.

JECA acknowledges that some things work best at a local or regional level. Local education programs, individual and organisational capacity building, assistance in putting people in touch with the right health professional all work best locally and these should continue to be 'bottom up' with both the service delivery and relationships managed locally. Volunteers and donors also require a meaningful local engagement if their support is to be sustained. Effective responses to state legislation and initiatives work best when relationships are managed at a state level. However we believe the gaps in health care and disability policies, medical and non-medical research, workforce training, advocacy and community awareness programs can only be addressed effectively through national investment.

^a See Appendix 1: The Joint Epilepsy Council of Australia

The time is right for a national approach, and for seeking national support from the Commonwealth Government and while we must continue to leverage State and Territory Government support for local, state specific activity, it is now time to redefine the paradigm of epilepsy care at a national level.

Aspirations for People Living with Epilepsy in Australia

JECA, as the national voice for all Australians living with epilepsy, strongly believes that people living with epilepsy are entitled to a quality of life no less than that expected by other Australians.

We believe this can be achieved by

Children, young people and adults with epilepsy:

- having access to integrated medical and non-medical specialist epilepsy services;
- achieving the highest possible levels of seizure control, if not seizure freedom;
- experiencing better educational and employment outcomes;
- enjoying increased opportunities to participate in community life; and
- acquiring the knowledge and skills to achieve their own wellbeing.

Families and support networks of people with epilepsy:

- are confident and knowledgeable; and
- have access to support and opportunities for networking.

We believe that the community needs to:

- better understand epilepsy;
- affirm people living with epilepsy as valued members;
- respond to the needs and aspirations of people living with epilepsy; and
- provide increased opportunities for participation.

We want the epilepsy sector, the medical and non-medical organisations across Australia to work together to:

- share knowledge and experience on creating positive change; and
- enable people living with epilepsy to live richer and more meaningful lives, thereby enjoying greater opportunities in education, employment and the community.

Priorities for Change

This submission highlights the initiatives required to stop Australia from slipping further behind other developed nations in addressing epilepsy as a public health issue. Where other conditions such as depression, cancer and AIDS have made great advances in community understanding, epilepsy has not.

This submission focuses on the minimum level of activity required to afford people living with epilepsy the same level of care as those with other chronic conditions.

This submission also highlights the need for national investment across research, workforce training, advocacy and community awareness programs.

The current support for the non-medical epilepsy sector is via state and territory governments. This support varies considerably across jurisdictions, with some states and territories providing no funding at all. The average funding per person with epilepsy across Australia is only \$8 per annum.

JECA recognises in 2009 the constraints of the current economic climate and wishes to work with all Australian governments to better utilise existing resources, initiatives and government programs to improve the quality of life of all people living with epilepsy in Australia.

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

Australia has examples of world's best practice in epilepsy care and it is now time to develop these islands of best practice 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 health reform process and to improve harmonisation of services across the States and Territories.

What is Epilepsy?

Epilepsy is the world's most common serious disorder of the brain, according to the World Health Organisation.¹ WHO reports that the burden of epilepsy accounts for 0.5% of the global burden of disease. This can be compared with multiple sclerosis at 0.1% or breast cancer at 0.4%, or diabetes at 1.3%.² The additional burdens are less calculable and include the effects on a family as a whole, the stigma and social exclusion experienced by those with epilepsy, missed educational opportunities, and underemployment or unemployment.

Key Facts

- A seizure is a disturbance of movement, feeling or consciousness occasioned by sudden, inappropriate and excessive electrical discharges in the brain.³
- Recurrent seizures usually attract a diagnosis of epilepsy.¹
- 10% of Australians will have a seizure during their lifetime, while 3–4% will be diagnosed with epilepsy.⁴
- Epilepsy occurs in both males and females.¹
- Epilepsy can occur at any age, but is more common in children and those over 65 years of age.³
- Epilepsy responds to medication in approximately 70% of people³
- Surgery and Vagal Nerve Stimulation Therapy may be appropriate treatments in some cases.³
- People with epilepsy have a mortality rate 2–3 times that of the general population.⁵
- Epilepsy is ranked in the top five causes of avoidable death in the 5–29 age group.⁶

Epilepsy is not just one condition; rather it is a diverse family of disorders comprising many seizure types. Seizures can be subtle causing momentary lapses of consciousness, or conspicuous causing sudden loss of body control. Seizures can be the cause of injury and even occasionally death. Seizures are episodic and unpredictable. They may occur as frequently as every day, or just occasionally in a lifetime. Although many individuals are essentially well between seizures, their lives are still constrained by the condition.

The causes of epilepsy are not fully understood, but factors affecting brain function including brain injury, developmental abnormalities, or genetic influences can lead to seizures. 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. Australian data sources quote international study figures, due to a lack of local data.⁷ 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.

Cumulative incidence (the number of people who will have epilepsy in their lifetime) provides a useful figure for discussion. Based on the current population of Australia of 22 million,⁸ this figure would be 660,000–880,000. The work by D'Souza,⁹ in establishing the Tasmanian Epilepsy Register, has begun to rectify the lack of Australian epilepsy data; however ongoing funding is required to advance this important work.

The Impact of Epilepsy

The onset of seizures can bring with it fear and uncertainty for the future. Reliable information may be hard to acquire and there can be difficult choices to make regarding medical treatment for oneself or one's child. If antiepileptic medication is required adverse effects of treatment can be experienced, increasing concerns about contraception, pregnancy, and cognitive functioning.

Injury and even death are potential risks, and as a result day-to-day activities may be restricted, depending on the frequency and severity of the seizures. Ongoing adjustments to lifestyle may challenge self-esteem, interfere with personal relationships and affect economic well-being.

Employment and education can both be further compromised due to lack of understanding by employers and educators.¹⁰ Driving restrictions are socially and economically disabling, especially in rural areas. Fear of seizures, seizure-related injury, and the misunderstanding of others are common reasons cited for avoiding public transport.¹¹ This compounds social, geographic and economic isolation for people with uncontrolled epilepsy.

Anxiety and depression may become serious additional issues to manage and lack of community understanding may lead to a strong sense of perceived stigma. Where epilepsy is severe, and especially where epilepsy is associated with old age or additional disability, the opportunities for independent living can be restricted with the potential for premature institutionalisation.

The serious level of epilepsy amongst Aboriginal and Torres Strait Islander peoples is evidenced by the over-representation of hospital admissions for convulsions and epilepsy, especially in the 15–24 years age group. Indigenous Australians of this age were hospitalised at over twice the rate of other Australians for this condition.

The elderly are the most rapidly growing segment of the population, and onset of epilepsy is higher in this age group than in any other. Adjustments to diagnosis, medication regimes and lifestyle can impact greatly on this population. Seizures may go unrecognised, or are misdiagnosed resulting in inappropriate treatment, while changes in living circumstances can compromise treatment and management.

Lived Experience of Epilepsy

“My seizures were incredibly disruptive and were largely uncontrollable for many years until a change of medication a few months ago has brought them under control. The medications were harder to deal with than the seizures. It took a lot of time and patience to get the right combination of drugs. The side effects were terrible, including mood changes, and a weight gain of 22 kilos within the first six months, and severe tiredness. My epilepsy is now sufficiently under control enabling me to study for a Nursing and Arts Degree at Australian Catholic University in Melbourne, although the memory loss is particularly frustrating.” *Elizabeth Cashin, Victoria*

“Diagnosed with complex partial seizures at the age of 12, antiepileptic medication did not completely control my seizures. Side effects of medication and seizures caused me to struggle with schoolwork, but with determination and hard work, I completed secondary school and then went to work. I was very upfront with employers about my seizures and believe being comfortable with this, gave some positive message to others. Not being able to drive was very frustrating. During my twenties my seizures worsened and my seizure type changed; I began having convulsions, at times without warning. By this time I was on four antiepileptic medications and was concerned about whether I could ever have children. I saw an epilepsy specialist and investigations found that I was suitable for epilepsy surgery. Even when the risks were explained, having the surgery was an easy decision for me to make. My seizures are controlled, and I now take far less antiepileptic medication. From time to time I have a little difficulty finding words, but it causes minimal disruption to my work and my life. I look back with no regrets! My life has turned around – I drive, have a job that I love working with the Epilepsy Foundation of Victoria, and I am now embarking on a new life journey: I am having a baby.” *Maree Kearton, Victoria*

“Titan was only 10 weeks old when he began having seizures. They were frequent and uncontrolled. Sometimes with as many as 20 a day and on one occasion he experienced 25 over a one and half hour period. We live in Darwin and as there is no dedicated paediatric neurologist, Titan was under the care of a paediatrician. The seizures were not stopping but the medication was being increased. No one knew what was happening and it seemed no one was willing to search for answers. Through the intervention of The Epilepsy Association of SA and NT Titan was eventually referred to the comprehensive epilepsy clinic in Melbourne and he is now thriving.” *Keith and Mai Darwin, NT*

“My dream was to join the armed forces, and even though I had epilepsy as a child, it had disappeared by primary school. However, in the first few weeks of very rigorous training, I had a tonic-clonic seizure and could not continue. This knocked me for six and I found it difficult to come to terms that my dreams were shattered. I picked up any job I could, but my seizures were uncontrolled and I would lose the job. I never went on the dole, but jobs became harder to get and I became financially compromised. I could not obtain accommodation and stayed with friends when I could. With the assistance of Epilepsy Association ACT, an appointment was arranged with an epileptologist who changed my medication and arranged for an investigation to determine if epilepsy surgery could help me. Eventually I had the surgery and it was a success. I got my life back, travelled to Europe and came home with Anna, who I met on a London bus. We now have a beautiful daughter, with another on the way. I have been seizure-free for the last two years and life could not be better.” *Iestyn, ACT*

“When our 4 year old daughter was diagnosed with epilepsy, we had no idea our lives would be turned upside down. Not knowing about seizures, Vanessa’s first seizure was a terrifying experience for our family. The stresses and uncertainties we have since experienced with her diagnosis have not been helped by the fact that we live in a small country town between Pt Lincoln and Ceduna. We were overwhelmingly isolated, with no help from medical services in the area. The Epilepsy Association of SA & NT helped put our minds at ease, to manage Vanessa’s condition and to get our lives back on track.” *Kylie Briffa, Lock, SA*

“I was diagnosed with epilepsy last year. I am a Registered Nurse and work at the RAH. I live in Golden Grove. Losing my licence was the biggest issue for me as I worked shift work and although my seizures were well controlled, I was still unable to drive. Catching a bus to work was not an option as there was no early morning service and I felt unsafe catching a bus at 11pm at night. Taking a taxi would cost me \$60 one way. Centrelink informed me that I was ineligible for a mobility allowance as “epilepsy is not an eligible disability” and yet someone I know who has a back injury and can drive has a mobility allowance just in case her back is sore and she cannot get into the car. I am lucky my family are supportive and help me with transport otherwise I would not have a job.” *Name withheld Golden Grove, SA*

“Having struggled with seizures since I was 15 years old, it was not until I was 32 that the frequency of my seizures forced me to give up work and apply for the Disability Pension. Until then I had been able to live independently and work as an assistant nurse in various nursing homes. Jobs were not easy to get, I had so many knock-backs which were soul destroying, but the places where I have worked have been understanding and willing to give me a go. To finally have to give up work because of my epilepsy was the worst time of my life. I underwent extensive investigations for epilepsy surgery, hoping that this would be an option for me, but the results came back that surgery was too risky for me. This news was devastating. However I had one option left – the implantation of a vagal nerve stimulator (VNS). Although this did not promise a cure, it had the potential to greatly reduce my seizure frequency. I underwent the procedure in 2002, and the results have been amazing. My seizure frequency reduced dramatically. In October 2008, I had a small seizure, but until then, I had been seizure-free for two years. For me, VNS has changed my life. In the past seven years since the VNS implant, I have returned to work and relinquished the Disability Pension, married my life-partner, honeymooned in the US. I now run a house, go shopping on my own, and can go out with the girls from work and not be frightened.” *Allison Johnston, New South Wales.*

“Epilepsy has made a huge impact regarding many aspects of my life, but the hardest area for me to overcome is the lack of employment opportunities, not due to the financial downturn, but because of my age, coupled with epilepsy, people are unwilling to employ me. I am 26 years old, a normal, intelligent, capable person who has been struggling to gain permanent part time employment for over 4 years. Prior to being diagnosed with epilepsy, I worked full time in office admin, but because of the lack of understanding and support of this condition that position became increasingly difficult as I could no longer work full time. My medication plays a big role in my inability to gain employment, I can't drive a car or use public transport and I rely entirely on my mother, who is also my carer, for all my mobility and supportive needs. As I have complex partial seizures, it is less apparent than other types of disabilities such as blindness, autism, wheel chairs etc. and this leaves me in a lesser position to receive assistance from Disability Employment Agencies, Their help towards me is very minimal but my epilepsy has a bigger impact than most people realise and greater assistance is needed.” *Davina Dove, Tasmania*

“I’m a painter. I’ve been sacked from many jobs after having a seizure – they look at you as if you have the bubonic plague. I’ve never lied to an employer about my epilepsy. I’ve even used the

services of the Antidiscrimination Commission and my union on occasion. I've found that employers aren't willing to be flexible with things like work hours. When you're out of work, your earning power is lost, not to mention the emotional and psychological distress associated with losing jobs and then trying to find another job. I haven't been able to get work for a long time, but am pleased to say I've just got one. Like many people living with epilepsy, I have many difficulties associated with accessing support through Centrelink. When I lost my job because I had a seizure at work, I found that I couldn't get a Health Care Card quickly enough to assist with my considerable medical and pharmaceutical expenses. I became so frustrated that I organised a petition seeking a change to Centrelink's qualifying period so that people with episodic and sudden changes to their health were able to get assistance sooner. The petition was distributed with support by Epilepsy Queensland and tabled in Federal Parliament a few years ago. Nothing seemed to come of it. I have been to talk to my Federal MPs but again didn't hear back from them. I live with my partner. I get really frustrated that the criteria for support are determined by my partner's income, and that when I've managed to save any money, this delays the time when I can start to get financial assistance. I wonder why someone who's tried to be responsible is penalised – if I'd spent all my money I'd get help sooner. My bills at the chemist are around \$120 per month, and this isn't as high as other people with epilepsy have to cope with. Epilepsy Queensland's been a great help to me over the years, but I wish the system gave people with epilepsy a fair go. *Gus (surname withheld), Queensland*

Epilepsy as a Public Health Issue

WHO states that '...it is doubtful if any medical condition has been so universally neglected, due to a combination of social stigma, low profile and lack of resources, as epilepsy.'¹²

Criticisms of epilepsy services have been made in many parts of the world.¹³⁻¹⁵

In the UK, Sir Liam Donaldson noted in the 2001 Annual Report of the Chief Medical Office¹⁶ that from 1953 five major reports had made recommendations to improve services for people with epilepsy but that services still remained patchy and fragmented. He stated that people with epilepsy '...are at triple jeopardy: they suffer social stigma because of their disease, understanding of the illness amongst health professionals is not high and the problem is not addressed by health services with the same commitment as is given to other chronic diseases...' Consequently services for people with epilepsy fall short of what might be expected in chronic disease management.^{16 p.23}

Dr Malcolm Taylor, a leading UK GP spokesperson on epilepsy, attributed the poor progress in the UK largely to the lack of neurologists in that country and the low priority given to epilepsy by health planners.¹⁷ The Chief Medical Officer of the UK, like Taylor, stated that service planners and policy-makers have not been moved by the plight of people with epilepsy, and this serious failure to act underlined the '...ignorance and apathy towards the needs of people with this common disorder'.^{16 p.4} In 2007 the UK All Party Parliamentary Group on Epilepsy in its report *Wasted Money Wasted Lives: The human and economic cost of epilepsy in England* stated that, '...even in this world of competing health interests, the case for improving epilepsy services is overwhelming.'^{18 p.4}

Low priority in public health, as an obstacle to the improvement of epilepsy care, has also been raised as an issue in the USA.¹⁹ The ratio of neurologists to patients is higher than the UK²⁰⁻²¹ but even so, the epilepsy and public health communities agree that epilepsy care is deficient. In 2004, a report from a national meeting of epilepsy experts noted a continuing lack of awareness regarding the seriousness of epilepsy and available treatment options among people with epilepsy, health care professionals, and the general public.¹⁹ The report also noted that, 'Despite its impact on the individual and society, epilepsy remains a hidden disorder, difficult to quantify and until recently, largely absent from the nation's public health agenda'.^{19 p.6}

It was not until 1994 that the US National Center for Chronic Disease Prevention and Health Promotion first convened a group of experts representing the epilepsy treatment and advocacy communities, to shape a public health agenda for epilepsy.¹⁹ Three years later the US Center for Disease Control and Prevention (CDC) sponsored the first major public health conference on epilepsy. The conference recommended that the goal of treatment should be 'no seizures no side effects' and the key message from the conference to the health care community was summarised as '...take seizures seriously; do it early and do it right the first time; be systematic, efficient and effective; and empower the patient'.^{19 p.7} The CDC has now identified powerful medical and social reasons why epilepsy should be considered as a public health problem in the USA.

In Australia, as in the USA, the ratio of neurologist to patients is higher than the UK.^{20, 21} However, it cannot be assumed that epilepsy services will therefore be adequate to meet the needs of Australian patients, taking account of the unique Australian environment and the distance to existing specialist care. Accurate assessment is difficult as there is no published data investigating the overall adequacy of Australian epilepsy services or the resulting outcomes for epilepsy patients. One known fact is that avoidable hospitalisations for convulsions and epilepsy generally increase with remoteness.²²

A perusal of the 2001-2002 data for Australian avoidable hospitalisations noted that ambulatory care-sensitive (ACS) conditions, accounted for 8.7% (over 552,000) of all hospital admissions in Australia.²³

Ambulatory care-sensitive conditions are classified as conditions for which hospitalisation is considered potentially avoidable through preventative care and early disease management.²³ For the years 2001–2002 the diagnostic category of ‘convulsions and epilepsy’ rated in the top ten ACS conditions for avoidable hospitalisations with 5.6% of ACS admissions. This can be compared with asthma at 7.4% and angina at 9%.²³ For the years 2001–2002, in age groups 0–14 and 25–44, ‘epilepsy and convulsions’ was the fourth most common cause of admission. In males however it was the most common cause of admission for the age group 15–24 (127.8 per 100,000), and the second most common cause for age group 25–44 (164.6 per 100,000).²³ The average number of days per patient is often higher for ‘convulsions and epilepsy’ (2.92 average days) than for angina or asthma (2.67 and 2.49 average bed days respectively).²³ However, no government policy response has yet emerged to address these figures. In the US, studies of hospitalisations for epilepsy estimate that many could be prevented with effective outpatient management, focusing on proper diagnosis, treatment and patient adherence.²⁴

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

Epilepsy is ignored in Australia-wide public health activities. It may be argued this is because epilepsy is a lower prevalence chronic condition. Nevertheless, even at a lower prevalence it is not an insignificant condition, as demonstrated in this report.

Epilepsy and other lower prevalence conditions such as multiple sclerosis, ALS (amyotrophic lateral sclerosis) and Parkinson’s Disease have raised questions for policy makers as to how best to effectively integrate their management into the framework of contemporary public health. Research in the US has investigated this issue with epilepsy as the case study in one project.²⁵ Overall findings indicated uncertainty by state health departments regarding their role in relation to lower prevalence chronic conditions (LPCC).^{25, 26} The studies identified reluctance by funded public health agencies to take the lead in initiating new programs for LPCCs such as epilepsy, when other priorities such as tackling risk factors associated with the leading causes of death demand their attention. One solution put forward is the increased involvement of organisations that are not traditional partners in health programs, such as community based support groups, with the goal of mobilising resources and expertise to collaborate with traditional health services and perhaps generate innovative outcomes.^{25,26}

Strategies

- *Support the ongoing operation and development of a national epilepsy register, building on the work already achieved in the Tasmanian Epilepsy Register.*
- *Support further epidemiological studies into prevalence and incidence of epilepsy and its impact on quality of life.*
- *Although not currently included in the discussion of chronic disease management in Australia, epilepsy is a condition in which patients can benefit from self-management training. Funding for epilepsy from current CDM budgets should be considered.*

Key Issues for Discussion

The Management of Epilepsy

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

Since 1960 a number of new antiepileptic drugs have been developed in line with better understanding of the pathophysiology of epilepsy.²⁷ In addition, greater availability of magnetic resonance imaging (MRI) has been a significant catalyst for improving the diagnosis and management of the condition, and assisting in refinement of surgical techniques.²⁸ Surgery is now considered as an early treatment option.²⁹ Research funding has gradually increased, with research findings underpinning ongoing improvements in care. However, estimates in the USA indicate that spending is still less per head than other neurological conditions.²⁹ Despite advances in the management of epilepsy, a recent worldwide snapshot of epilepsy care found it to be grossly inadequate compared with the needs in most countries and, as might be expected, the low-income countries have extremely meagre resources.³⁰

Patients who experience seizures, either new onset seizures, or recurrent seizures, will often present to the Emergency Department (ED) for treatment. They may be admitted for further care or referred on for follow up and non-emergency assessment. Authors have found that although seizure disorders are common in the emergency department, the management in this setting is not always optimal, with variations between physicians and departments.³¹⁻³³ In addition, the patient presenting with a possible first seizure, and no prior history or treatment, presents a particular diagnostic challenge.³⁴ To promote continuity of care and ensure the best possible long term outcome for all seizure patients, suggested strategies for ED management include: evidence based guidelines for systematic diagnostic evaluation, appropriate and thorough referrals, and timely provision of information on issues such as driving.³⁵⁻⁴⁰ It is of interest to note that a recent UK study found that there is a relatively strong relationship between the quality of epilepsy management in primary care (proportion of seizure-free patients) and epilepsy related emergency hospitalisation.⁴¹ This suggests that quality primary care can lead to a minimisation of epilepsy-related hospitalisation.

Primary care practitioners are the key interface between patients and a health care service. However, because the incidence of epilepsy is modest in comparison with many day-to-day illnesses, it is unlikely that primary care practitioners will see a large number of cases. Consequently, given the diversity of the condition, it is difficult for primary care physicians to develop their skills in epilepsy care, especially in the area of diagnosis or initial treatment.⁴² Nevertheless patients rely on them. Recent unpublished Australian research into new onset seizures identified that where there was no epilepsy support worker the GP was seen as a key source of information.⁴³ For continuing management, a primary care base, closely integrated with specialist epilepsy services, has been put forward by many in the UK as the ideal model of epilepsy service provision.⁴⁴ This resembles the current framework of Australian care.

However, such a model requires epilepsy expertise at both levels of care as well as effective strategies for integrated management and Australia lacks formal national guidelines. The recently published UK clinical guidelines for the diagnosis and management of epilepsy offer positive leadership.^{45,46} For example, in new onset seizures the guidelines recommend referral to a neurologist specialising in epilepsy within two weeks. Currently, in Australia this is almost impossible to achieve outside the CBD in even the most populous states.

A number of opportunities exist to improve the health management of epilepsy. The first is through the current reform process of the Australian health system. Four themes have been identified by the interim report of the National Health and Hospitals Reform Commission 'A Healthier Future for All Australians'.⁴⁹ These are:

- Taking responsibility to build good health and well-being by families, communities, health professionals, employees and governments;
- Connecting care over the lifetime of a person's illness;
- Facing the inequities of health; and
- Driving quality performance

Although epilepsy varies markedly between individuals, in many cases the condition fits the definitions given for chronicity.⁴⁷ However, in Australia while it has been included in a summary of child health, it is not mentioned in the National Chronic Disease strategy.⁴⁸ If epilepsy was included under the umbrella of chronic conditions, people with epilepsy might be expected to benefit from the increased funding of research and development of chronic disease management (CDM) now taking place.

Perhaps epilepsy has been overlooked because it lacks well-defined links to commonly accepted lifestyle factors associated with CDM. Nevertheless, whilst epilepsy may not fit easily into a generic CDM program, issues such as better understanding of one's condition, improved self-efficacy and enhanced doctor-patient communication, which are all features of chronic disease self-management, would benefit people with epilepsy.

People with epilepsy have been invisible in health policy⁵⁰ and the opportunity now arises for their needs to be recognised within these themes. In order to create high quality outcomes, coordinated care across primary, tertiary and specialist services is an area that requires addressing. There is evidence that many people with epilepsy experience inequalities that go beyond the health system affecting their working and family lives.⁵¹

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.

The episodic nature of epilepsy often makes it difficult for people to meet the eligibility criteria for access to social services. In the case of the newly diagnosed, or those who experience breakthrough seizures, the interim period required to stabilise on medication can result in loss of employment or diminished employment. The interval between registering and receiving benefits can be financially crippling due to the immediate need of high cost medical visits, medications, and alternative transport costs. A second opportunity exists to address such inconsistencies through the Health, Community and Disability Services Ministerial Council, which operates as a plenary forum of the Australian Health Ministers Council.

The Australian epilepsy non-medical sector has historically taken responsibility for building good health and wellbeing within the epilepsy community. This continues to be undertaken without direct federal funding in any state or territory. While some states receive funding from their state government, there is a high level of variation in funding between states.

The following analysis of 2007/8 financial year total revenue and government funding for the non-medical sector demonstrates the variation:

- in the amount of government funding per annum
- in funding per person with epilepsy per annum
- in the amount and percentage of non-government funding raised

	Total Organisation Revenue \$	Total Government Funding \$ (State)	% Government Funding	Population Dec 2008	Government Funding per capita	Government Funding per PLWE (@1%)
ACT	108,724	67,280	62%	348,000	\$0.19	\$19
NSW	4,414,246	193,463	4%	7,041,000	\$0.03	\$3
QLD	928,563	368,671	40%	4,349,000	\$0.08	\$8
SA/NT	2,471,601	0	0%	1,833,000	\$0.00	\$0
TAS	176,960	130,593	74%	500,000	\$0.26	\$26
VIC	4,069,015	883,302	22%	5,364,000	\$0.16	\$16
WA	77,880	0	0%	2,204,000	\$0.00	\$0
	12,246,989	1,643,309	13%	21,639,000	\$0.08	\$8

Strategies

- *Ensure equity in government funding for people living with epilepsy across Australia*
- *Examine existing frameworks for delivery of epilepsy care, including access to Comprehensive Epilepsy Centres with epilepsy surgery, throughout Australia. Identify areas for the improvement and development of appropriate strategies.*
- *Advocate that the health reform process recognise epilepsy health and medical services have been long neglected and require reform in their own right with particular regard to:*
 - *The coordination of primary, specialist and tertiary services.*
 - *Evaluation of clinical pathways such as existing clinical pathway for epilepsy management at the Royal Melbourne Hospital and assess its suitability as a model for other settings.*
 - *Education of all other Primary Care providers including the resourcing of general practitioners, and nurses.*
- *Develop more consistent and coordinated health, welfare and disability services across all States and Territories and become part of the agenda of the Health, Community and Disability Services Ministerial Council.*
- *Develop Australian guidelines for the management of epilepsy with the participation of all key stakeholders.*
- *Explore with general practice, requirements for effective participation of GPs in the care of patients with epilepsy. In conjunction with general practice develop web resources for inclusion in GP ehealth initiatives.*

Self Management – Person Centred and Directed

JECA members have always carried out information and support programs as part of their core business. Although research is lacking in this area, the service is considered to assist with adherence, and therefore contribute to seizure minimisation and possible hospitalisation.

These programs are in fact addressing issues of person directed management, but they are not recognised or funded under existing chronic disease management programs. In the UK the Expert Patient Program, which promotes patient self-management has drawn on the experience of patient support agencies. Funding has been provided for an epilepsy pilot program. In the US research is evaluating creative options for program delivery through telephone. Such service could be beneficial where distance restricts face-to-face activities.⁵²

Strategies

- *Evaluation of international epilepsy person directed programs.*
- *Investigation of Australian Emergency Department data to identify factors that contribute to hospital presentations, with data used to inform ongoing epilepsy self-management program development in Australia.*

Stigma

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. Bagley⁵³ suggests that the person with epilepsy is ‘...feared and hated because he did what we are afraid we will do ourselves. He loses control – basic control of his motor movements. He reverts to the ‘primitive’, so that the punishment of him (by social rejection and ostracism) appears to be justified’.^{53 p.38} 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.^{54,55} Diverse examples of stigma and discrimination have been documented internationally^{56,57} and the impact of stigma in epilepsy has been included as an outcome measure in a number of studies.⁵⁸ In Australia, the Human Rights Commission reported that epilepsy is often experienced as a severe social handicap due to the stigma attached to it.⁵⁹

Accurately gauging the extent of enacted stigma and public discrimination against people with epilepsy is challenging. In surveys there may be differences between how people say they behave, and how they do behave. Perceived stigma can lead people to disguise or hide their epilepsy⁶⁰ and it is also often associated with dysphoria, anxiety, low self-esteem, helplessness, and somatic symptoms.⁶¹ Dilorio et al⁶² found perceived stigma to coexist with negative beliefs about management of epilepsy and Jacoby⁶³ also found a cluster of negative psychosocial scores associated with stigma in epilepsy. Nevertheless, evidence of association does not establish a direct causal link.

To avoid a stigmatising diagnosis of epilepsy, individuals may avoid medical assessment, or choose non-compliance with treatment so as not to confirm or reveal their condition through adherence to a treatment regime. Such strategies may increase seizure-related risks. They can also lead to increased anxiety and add to the sense of shame. Ironically, the actions of health professionals can negatively affect a patient’s perception of epilepsy⁶³ therefore management strategies need to be carefully assessed to ensure they do not exacerbate a sense of stigma. Similarly, encouraging a person with epilepsy to hide their condition, for example, may seem to be a pragmatic strategy. However, the suggestion attaches a level of unacceptability to the condition, which the person with epilepsy may not have otherwise felt, and can be described as stigma coaching.⁶³ Saylor and Yoder⁶⁴ outlined an alternative approach for health professionals, arguing for a model of health care characterised by a more equitable sharing of power and goals. They suggest that the manner in which health care is delivered may increase or decrease the effects of stigma.

Encouraging a client’s participation in health care decision-making is an outward demonstration of respect and regard for that person. Treating a client as a partner in establishing goals demonstrates one’s acceptance of the individual as valuable. On the other hand, when health providers make decisions regarding treatment of goals without consulting a client, they reinforce the client’s feelings of being discredited. Therefore, any mode of delivery that increases client participation enhances that person’s perception of self-worth and therefore reduces the effects of stigma.^{64 p.15}

Despite a stream of information describing the relationship between stigma and epilepsy, investigative studies of interventions to reduce stigma are limited.⁶⁵ However, theories have been proposed. Morrell,⁵⁶ like Saylor and Yoder⁶⁴ focuses on medical services, although the emphasis is on content rather than framework. She argues that the reduction of epilepsy related stigma would be one outcome of good quality medical care, rapid seizure control, and accurate information for the community as a whole.

With this in mind, it is interesting to consider two studies. The first included people who had been seizure free for two years, of whom 14% returned a positive score for felt stigma. Subjects scoring high for stigma were more likely to have been seizure free for less time. They were also more likely to worry about their condition and to have low scores for health status.⁶⁶ In the second study, in a cohort of newly diagnosed epilepsy patients, approximately one quarter of respondents reported feeling stigmatised. At the two year follow up, of those who were still having seizures, 44% reported stigma, while of those without seizures, 14% reported stigma.⁶⁷ This evidence suggests that freedom from seizures may reduce the sense of stigma.

Activities specifically aimed at targeting stigma in epilepsy are now being promoted by the US Centers for Disease Control, which illustrate the importance being given to stigma in the public health arena. However key authors on this topic have noted a range of issues which must be considered if change is to occur, for example, any education process needs to involve not only the affected individual, but also family, friends, educators, potential employers, health insurers, the media and policy makers.⁵⁶ Strategies for interventions need to be both epilepsy-specific and culturally specific,^{58,68} and intervention-outcome studies will need more clearly defined outcome measures of stigma.⁶⁹

The extent to which stigma adversely affects the quality of life of people with epilepsy in Australia is under-researched. In 2006 Brown explored the effects of stigma through the National Health Survey where he was able to compare responses to a number of conditions. He found that people with epilepsy were far more likely to be unemployed, to have never married and to be divorced compared to people with other conditions. People with epilepsy also recorded higher levels of psychological distress.⁵¹ These data based on a relatively small Australian sample indicate that stigma in epilepsy remains a problem in Australia.

Brown has called for further Australian research so that this can be the basis for targeted community awareness campaigns to improve Australians' attitudes towards epilepsy.

Strategies

- *Increase epilepsy awareness and understanding across all sectors of the community.*
- *Provide appropriate epilepsy care, which successfully minimises seizures thereby reducing the likelihood of perceived stigma.*
- *Undertake further applied social research into the extent and impact of stigma both on the community and on people with epilepsy.*
- *On the basis of results of these research projects, develop targeted community awareness campaigns and training programs that can be delivered in any workplace, including schools and universities.*

Anxiety and Depression

Psychiatric disturbance in patients with epilepsy tends to be under-recognised. This failure to act on psychiatric symptoms may be due to both the clinician and patient minimising the significance of the symptoms, because they consider depressive and anxiety symptoms a reflection of normal adaptation to the condition,⁷⁰ or to a belief that treatments are ineffective, or will exacerbate seizures.⁷¹ In a review of psychiatric comorbidity in chronic epilepsy, published in 2000, the authors commented that ‘...there is presently only a preliminary understanding of the additional burdens posed by comorbid psychiatric disorder in chronic epilepsy, even though these burdens seem to be significant.’^{72 p.S36} The authors concluded that mood disorders were the most common lifetime-to-date diagnoses in such patients followed by anxiety disorders. Major depression was found to be the most prevalent of the mood disorders.⁷² A growing awareness of the importance of this issue was evident at the Second National Conference on Public Health and Epilepsy in the US,¹⁹ where recognition of the substantial psychiatric comorbidity in people with seizure disorders or epilepsy led to identification of this as a priority area for action.⁷³

The epidemiological data describing depression in epilepsy is varied, and subject to ongoing debate due to diverse research methodologies and sample populations with potential selection bias and self-reported diagnoses.^{74,75} Under reporting of symptoms by patients and under diagnosis by clinicians, also contributes to poor quality information.⁷⁶ Nevertheless, published studies indicate a prevalence of 20-55% in patients with recurrent seizures and 3-9% in patients with controlled epilepsy.^{76, 77} When the psychiatric comorbidity in epilepsy is compared to psychiatric comorbidity in other neurological conditions, the rates have often been found to be comparable^{61,78,79} However, a US population based study into the lifetime prevalence of depression, epilepsy, diabetes, asthma and other chronic medical disorders found higher rates of depression in those with epilepsy than healthy respondents and those with diabetes and asthma.⁷⁹ A community based study assessing the frequency of depression symptoms in a sample of epilepsy, asthma, and healthy control subjects, also found that people with epilepsy had higher depression scores than those of either the asthma or control group.⁸⁰ When assessing the relationship between depression and epilepsy it is apparent that the relative significance of, and the interaction between, neurobiological, iatrogenic and psychosocial factors are inadequately understood.^{71, 81}

There are also methodological difficulties in assessing the prevalence of anxiety disorders in people with epilepsy, and studies suggest varied rates.⁷¹ Hospital-based studies have found prevalence rates of around 30%⁸² and 53%.⁸³ Community-based studies however, have produced lower rates, up to 25%⁸⁴ and 20.5%.⁸⁵ Lower figures, which were nevertheless elevated compared to those in patients without epilepsy, were found in a particularly large UK national community-based study of primary care records. Comparing epilepsy patients with all others, the rate of anxiety disorders in 5834 people with epilepsy was 11%, compared to 5.6% in 831,163 people without.⁸⁶ In children, a study by Ettinger et al. found 16% met criteria for significant anxiety symptomatology.⁸⁷

The understanding of anxiety in epilepsy is challenged by the same complex interrelationship of similar neurobiological, iatrogenic and psychosocial factors that are associated with depression and epilepsy.^{61,85,88,89} Despite the indications that identification and treatment of anxiety is important to patient outcomes,⁹⁰ recognition and treatment of anxiety remains inadequate.⁸⁹ Treatment of anxiety can be effective in people with epilepsy, without compromising the management of the epilepsy.⁸⁶ However, while recognition, understanding, and treatment of anxiety symptoms and disorders remains suboptimal, chances to improve overall outcomes and quality of life of people with epilepsy will be missed.⁸⁸

There is a need for anxiety and depression in people with seizures to be better identified and treated. However, most epilepsy clinics are limited in their number of staff and it is rare for an epilepsy clinic to have ready access to a counsellor or psychologist, let alone a psychiatrist.

Strategies

- *Ensure adequate psychological services for patients with epilepsy.*
- *Encourage and support research into the psychological impact of epilepsy*
- *Ensure adequate training and information for health professionals working with people who have epilepsy, regarding the incidence and management of comorbid anxiety and depression.*

Indigenous, Cultural and Social Issues

There are both generic and epilepsy specific influences affecting the social and political aspects of public health. A report on epilepsy in Northern America concluded that poor treatment access and health care disparities for people with epilepsy may be related to insufficient economic resources, rural isolation, gender and ethnicity, as well as lack of public and physician knowledge of modern approaches to epilepsy care.⁹¹ Australian studies have noted that Indigenous Australians present more frequently to hospital with neurological conditions than non-Indigenous Australians,⁹² and that they present with more serious disease.⁹³ Reasons put forward include not only possible ethnic differences in prevalence,⁹² but also inequitable health care utilisation due to cultural or geographic issues.⁹³

For all Australian states combined, in the two-year period from July 2004 to June 2006 'convulsions and epilepsy' was reported as the most common category of admissions to hospital amongst Aboriginal and Torres Strait Islander peoples aged 15–24 years. Indigenous Australians of this age were hospitalised at over twice the rate of other Australians for this condition. Convulsions and epilepsy accounted for approximately 1% of total hospitalisations of Indigenous Australians aged 15–24 years.⁹⁴

JECA acknowledges the serious level of seizures/epilepsy in Aboriginal and Torres Strait Islander peoples. Educational initiatives have been undertaken, but very limited funding and difficulty servicing the affected populations from the existing JECA network has severely restricted opportunities for further action.

Strategies

- *Facilitate research into the serious issue of seizures/epilepsy in Australian indigenous health with a view to urgent action.*
- *Increase resources to expand education initiatives already undertaken by JECA.*

Epilepsy-related Death

There are approximately 300 epilepsy-related deaths in Australia each year.⁹⁵ Death in epilepsy can be caused by a range of factors, including status epilepticus, seizure-related injury and accidents, suicide and treatment-related deaths. The most frequent cause of epilepsy-related death is Sudden Unexpected Death in Epilepsy (SUDEP). The term SUDEP applies to sudden death occurring in a person with epilepsy for no apparent reason. A high proportion of the people who die are young adults. Often they are found dead in bed and it is family and friends who make this shocking discovery. Historically such deaths were often attributed to some form of asphyxiation but it is now known that this is not the case. When such a death occurs and all other possible causes of death are excluded, SUDEP is usually attributed as the cause of death.⁹⁶ The increased attention to SUDEP has largely resulted from the persistent work of bereaved families in the UK distressed by the loss of loved ones and puzzled by the lack of knowledge about this phenomena. In conjunction with some supportive clinicians these families persuaded the UK government to establish an audit into epilepsy-related death, which was published in 2002.⁹⁷ The report identified almost 1000 epilepsy related deaths of which approximately half were SUDEP. The report suggested that many of the deaths may have been preventable, highlighting inappropriate care as a contributing factor. The audit appears to have energised the public discussion about epilepsy, generating debate as to why epilepsy care is inadequate and how best to rectify this situation. Subsequent research has begun to identify risk factors but the cause is still elusive.⁹⁸

Epilepsy Australia has collaborated with Epilepsy Bereaved to provide information to members, the community and bereaved families. In Victoria there has been collaboration with the Victorian Institute of Forensic Medicine to raise awareness amongst health professionals, to improve the haphazard identification and reporting of SUDEP, and to provide support to people in the community affected by SUDEP. In 2005 Epilepsy Australia, supported by Epilepsy Bereaved, produced the internationally recognised *Sudden Unexpected Death in Epilepsy: A global conversation*.⁹⁹

Research into SUDEP is developing but has attracted almost no support in Australia. Unfortunately a world first pilot research project of death scene investigation in SUDEP by VIFM, modelled on Sudden Infant Death Syndrome (SIDS) research has not been able to develop due to a lack of funding. Epilepsy Australia has established a research fund to support such initiatives and to stimulate additional research. SIDS provides a very interesting comparison to SUDEP with striking similarities between the two phenomena. Both have no identified cause; only risk factors are suggested. In the case of SIDS, action on risk factors has reduced deaths. A comparison of research funding provides a stunning contrast. Whereas SUDEP has received virtually no Australian research funding, SIDS has accessed more than \$15m for research.¹⁰⁰ The Australian death rate of SIDS has fallen from 563 in 1986¹⁰¹ to 87 in 2005¹⁰². This is far below the current estimate for SUDEP of 150 deaths per year, and JECA believes with the same level of support and focus a similar reduction could be achieved in relation to SUDEP.

A recent report into avoidable mortality in Victoria between 1997 and 2003 found that epilepsy was in the top five causes of death. It is of interest to note that the four top causes were all accident-related or due to self-harm. Epilepsy was the only chronic condition listed in the top five.⁷

Strategies

- *Educate people living with epilepsy, families, and health professionals about SUDEP and its risk-management.*
- *Facilitate and support urgent research into SUDEP and its association with epilepsy management.*
- *Promote awareness of SUDEP amongst health professionals and emergency response teams.*
- *Encourage greater consistency in the certification of death to assist in national monitoring of SUDEP and other epilepsy-related deaths.*
- *Extend and promote the support services for people bereaved by epilepsy*
- *Promote risk-management education to reduce avoidable death in epilepsy.*

Injuries

Injuries related to epilepsy have received only modest research attention, with variations in study samples and techniques possibly contributing to lack of consistency in the data.^{103,104} Overall there appears to be a slightly increased risk of injury for people with epilepsy, with minor injury predominating.¹⁰⁵ Certain factors such as seizure frequency and type do increase risk, especially in situations involving water, such as swimming and bathing, and Australian reports endorse this finding.^{103,106,107,108} However, studies suggest that the more serious injuries such as severe burns, head injuries and motor vehicle accidents may have been overestimated.^{107,108}

These findings do not reflect the experience of epilepsy workers in Australia. In Unsworth's Australian sample, nearly half the respondents reported that they had experienced a seizure-related injury yet there was limited knowledge of seizure-related injury minimisation strategies amongst respondents.¹⁰⁹

Strategy

- *Conduct research into epilepsy-related injury and identify effective preventative strategies.*

Education

Epilepsy is a chronic disorder that significantly affects education outcomes. Retention rates are generally lower, with one Australian study reviewed by Walker finding that people with epilepsy were far less likely to complete secondary education and progress to tertiary education.⁵⁰ Various psychosocial, medication-related, and epilepsy-related factors have been shown to be associated with learning disabilities in epilepsy.¹¹⁰

Children with epilepsy often experience difficulties at school, due to cognitive impairment, the effects of their medication on their ability to learn, absences due to seizures, hospitalisation or medical appointments, and the stigma associated with epilepsy can make it difficult for them to feel included with their peers.

A US study that looked at the academic achievement in children with epilepsy or asthma, found that children with epilepsy had significantly lower achievement scores than children with asthma. Boys with severe epilepsy were most at risk for underachievement.¹¹¹ Reasons for academic underachievement in children with epilepsy who do not have learning difficulties, are not clear. Variations in learning styles may not be taken into account, and the effects of seizures on school performance may not be well understood. Walker found that other factors contributing to under-achievement related to teacher attitude and expectation.⁵⁰ A recent study on teacher's knowledge and attitudes towards students with epilepsy found there were significant deficits in terms of general knowledge about epilepsy, its impact in educational settings, and the appropriate management of epilepsy and seizures in the classroom.¹¹²

A study looking at the perception of epilepsy among children aged 9-11 years found that their perceptions of epilepsy had a negative connotation that 'may reflect society's collective unconsciousness of the prejudice toward epilepsy and people with epilepsy'.¹¹³ In its efforts to promote positive attitudes towards epilepsy amongst Australian school children, JECA conducts the epilepsy-friendly schools program in several states across Australia, which in the past year engaged up to 48,000 primary and secondary school students, their families and teachers.

There is substantial opportunity to improve school completion rates for people with epilepsy which will improve their chances of meaningful employment.

Strategies

- *Undertake research into the impact of epilepsy on learning. This should include applied social research on attitudes of teachers, parents and school organisations.*
- *Identify and implement an effective epilepsy friendly education environment that includes the training of teachers in understanding epilepsy and emergency management.*
- *Expand the epilepsy-friendly schools program to reach all school children in Australia by removing the need for the school community to be involved in fundraising to access this program.*

Employment

JECA members have recorded much anecdotal data regarding the negative effect of epilepsy on employment outcomes, however, there is little research data on this matter. In a review by Walker⁵⁰ it was noted that research had found people with epilepsy were at least three times more likely to be out of the workforce than people with other chronic illnesses, when all other important factors such as age and gender were held constant.

A UK study found people who were newly diagnosed, or who had recently experienced a single seizure, or who had early onset epilepsy, were exposed to substantial employment disadvantage.¹¹⁴ Greater efforts are necessary to help these people return to work and stay employed.

Despite this somewhat bleak overview, people with epilepsy have been found to be employees whose workplace attendance was equal to others. They were not more accident-prone and took no additional sick days compared to their colleagues.¹¹⁵ Nevertheless people with epilepsy were hindered in the progression of their professional careers, receiving lower salaries for a comparable job.¹¹⁵

Stigmatisation in the workforce is common and can affect employment, career advancement, and personal and professional relationships with colleagues. A US survey asked 74 employees at two New York companies about their comfort level working with colleagues who had depression, multiple sclerosis, or epilepsy.¹¹⁶ The potential of working with someone with epilepsy and having to provide first aid elicited more anxiety than did working with or providing first aid for someone with depression or multiple sclerosis. Participants were particularly worried about the unpredictability of the person having a seizure.

A recent survey in the UK of employers from various industries showed that 44% considered epilepsy in employees a 'high concern'. Fifty-six percent responded that they felt fewer than one third of the positions in their companies could be filled by individuals with epilepsy, and 21% thought that epilepsy would be a 'major issue' in the hiring decision of a prospective employee.¹¹⁷

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.⁵¹ 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.

Strategies

- *Implement an education program targeted at employers and employment agencies that dispel the myths and misunderstanding surrounding epilepsy to help promote an epilepsy friendly work environment.*
- *Development of a national strategy within government agencies ensuring staff fully understand epilepsy and its impact on the person in order to address their individual needs.*

Driving / Transport

People with a history of seizures and epilepsy are subject to driving restrictions because the risk of unconsciousness or loss of awareness during some seizures increases the possibility of accidents.

Much hard work continues to be done by the Epilepsy Society of Australia and driving licence authorities to develop fair and safe driving guidelines for people with epilepsy, balancing the risks of seizures against the need for personal and community safety. National driving guidelines have been established and can be found at the following link <http://www.austroads.com.au/aftd/index.html>.

Many people with well-controlled epilepsy are legally able to drive. For some people with epilepsy, however, there are periods when driving will not be possible. Sudden and unexpected loss of the right to drive can be catastrophic. If a person feels well and does not fully understand the risks, the pressure to defy driving regulations is considerable. Fear of extended restrictions may discourage disclosure of seizures to their doctor.

Access to community transport programs is sometimes restricted due to the uncontrolled nature of some forms of epilepsy and the limited operational hours, particularly in rural and regional areas. Public transport is not always a suitable alternative as a seizure on public transport can leave a person vulnerable to injury, theft and/or assault, and subject to negative public reactions. An Australian survey in 2007 found that 40% of people with epilepsy avoid public transport either occasionally, sometimes or always.¹¹ Some transport funding is available throughout Australia for subsidised taxis but this is less than adequate due to the difficulties in meeting the established criteria.

In many cases short term financial assistance, or tax relief, to assist with transport costs would greatly relieve the personal and financial stress on individuals. This would allow them to maintain some sense of normality while care is instituted and seizures brought under control. For those whose seizures prevent driving for long periods, and perhaps indefinitely, the lack of mobility can greatly decrease their quality of life and create barriers to social participation, especially in rural areas.

Strategies

- *Implement policies and guidelines to ensure adequate and rapid access to mobility allowances for people with epilepsy and those undergoing seizure investigation whose ability to drive is restricted.*
- *Develop national standards to ensure equitable access to transport for all people living with epilepsy regardless of state or region.*
- *Support the finalisation and adoption of national driving decision-tree and guidelines as proposed by the Epilepsy Society of Australia (ESA).*

Gender-specific Issues: Men

Gender has an important role in how epilepsy impacts on the person with unique issues for men. While adherence to antiepileptic medications and lifestyle adjustment issues are not gender specific, it is well recognised amongst epilepsy community service providers that young men especially struggle with these issues.

Men with epilepsy are at risk of decreased sexual functioning, including sexual interest and sexual performance.^{118,119}

Although there is only a slightly higher incidence in epilepsy of males to females, some Australian data shows an interesting gender bias in figures relating to epilepsy care, with a higher representation of males to females. First Seizure Clinics studies in two states found males made up two thirds of those presenting to the clinic with a diagnosis of new onset seizure or epilepsy.⁴³

Data from Australian Ambulatory Care Sensitive (ACS) admissions show the category of 'convulsions and epilepsy' was the most common cause of admission for males in the age group 15-24 and the second most common cause of admission for the age group 25-44.²³ Australian mortality data reveals that 61% of epilepsy deaths are male.⁹⁵

Strategies

- *Conduct research into gender bias and whether service provision is appropriately structured to meet the needs of males.*
- *Educate men with epilepsy about lifestyle issues, adherence to medication, and the possible impact of epilepsy and antiepileptic medication on sexual functioning.*

Gender-specific Issues: Women

Gender has an important role in how epilepsy impacts on the person with unique issues for women. Epilepsy and its treatment in women have implications for the menstrual cycle, contraception, fertility, and reproduction.

Women of childbearing age need to be given an early explanation about epilepsy and its possible impact on bearing children, including an informed discussion on the risks of inheriting an epileptic tendency, the risks associated with antiepileptic drug (AED) treatment during pregnancy, and lifestyle management.¹²⁰ Unplanned pregnancy is a concern for any woman on AED treatment. Pre-counselling must address reliable contraception and optimisation of AED treatment to minimise the risk of developmental malformation while maintaining seizure control.^{121,122} Such counselling should include information regarding the benefit of folate supplements. An Australian study has found that the risk of neural tube defects in the foetus is significantly higher for women with epilepsy than the general population.¹²³

Many women with epilepsy are anxious about childbirth, the safety of breastfeeding while taking AEDs, and their ability to care for their child. Treatment challenges for the specialist during pregnancy can be a balancing act between the risks of foetal exposure to the potential risks of AEDs and the maintenance of maternal seizure control.¹²⁴ Pregnancy registers around the world, including the Australian Pregnancy Register,¹²⁰ prospectively collect data related to the outcomes of pregnancies in women with epilepsy. Best practice in managing epilepsy and pregnancy dictates close monitoring by a neurologist specialising in epilepsy pre-pregnancy, during the gestational period and at time of delivery.¹²⁵ For those women living in regional and remote areas of Australia, access to this recommended level of optimum care is limited with evident opportunities for an improvement in information and services.

Access to support when the mother and baby are discharged home is another time of high risk and need. Sleep deprivation, hormonal changes and the challenges of being a new mother can increase the risk of seizures placing both the mother and baby at risk.

Strategies

- *Targeted adolescent and family planning programs for women with epilepsy to increase awareness of gaining pre pregnancy counselling to be included within existing programs.*
- *Extend eligibility for the Specialist Childcare Benefit to enable in home childcare and provide mothers with epilepsy greater access to in home respite.*
- *Ensure that women with epilepsy, especially those living in rural and remote regions of Australia, have timely access to the specialist treatment required in line with world's best practice.*
- *Encourage support for the Australian Pregnancy Register through publicity and funding.*

Disability Support Services

Epilepsy is the most common medical condition in adults with an intellectual disability. Not only is it common, it is often refractory and severe¹²⁶ resulting in reduced quality of life and increased carer stress. Many clients of disability support services therefore have epilepsy, as a primary or co-morbid condition. Advocacy on behalf of these clients and training of carers and support staff has always been a significant area of activity for JECA.

Parents of children with epilepsy and other conditions/disabilities have reported that disability is also a barrier to quality health care. They may not be referred for investigative procedures due to assumptions about their inability to cope and cooperate, and where particular treatments are scarce (e.g. Vagus Nerve Stimulator), the person with a disability may be put at the bottom of the waiting list, with little chance of ever making it to the top. Sometimes parents are asked to stay with the child 24/7 because nursing staff say they don't have the capacity to look after the child in hospital. This places a heavy burden on families who may have already been looking after their child 24/7 prior to hospitalisation.

The disability sector needs are complex and JECA has developed a level of expertise in response to these needs, especially in the development of quality epilepsy management plans and the delivery of emergency medication training. Limited government funding has restricted the extent of this work throughout Australia.

There have been significant enhancements in the provision of services to people with disability in Australia in recent years, with changes fostering personal dignity and rights. Further understanding is needed about the management of epilepsy and those with an intellectual disability.¹²⁶ Supporting disability services to implement appropriate support for people living with epilepsy is essential.

Greater interaction between the states could lead to cost effective program development in areas such as the training of disability support workers in understanding epilepsy, developing quality management plans and emergency medication delivery. State based expertise could be shared with national benefits. However with the limited funding available in all states most local agencies have the delivery of local service as their top priority and the allocation of resources to national development tasks have been restricted.

Strategies

- *Ensure ongoing evaluation of utilisation of services in the disability sector by people with living with epilepsy.*
- *Review of assessment criteria for benefits for people living with epilepsy.*
- *Facilitate research into the needs of carers and families responsible for the care of children and dependent adults with epilepsy and a disability.*
- *Seek additional funding to foster national collaboration between JECA and the disability service sector to develop a national disability training program on epilepsy.*

Ageing Population

The elderly are the most rapidly growing segment of the population, and onset of epilepsy is higher in this age group than in any other. The incidence of a first seizure is 52 to 59 per 100,000 in persons 40 to 59 years of age, but rises to 127 per 100,000 in those 60 and over.¹²⁷

Seizures in older people often go unrecognised, since the temporary loss of concentration or a state of confusion may be attributed to 'old age' dementia, or other neurological conditions. Misdiagnosis and inappropriate treatment often occurs in older people. Falls in this age group can be attributed to a range of factors and seizures may not always be considered.

The social circumstances of the person can impact considerably on the management of epilepsy, eg. living alone, loss of a partner, loss of ability to drive or living in an aged care facility.

Many older people take a number of medications where drug interactions and dosage issues are critical. This has particular implications for the medical management of epilepsy in older people, especially those living in aged care facilities. If the resident of an aged care facility does not manage their own medication, the AEDs provided may be inconsistent as to the formulation supplied. Both branded and generic formulations may be supplied at different times, and this has been associated with toxicity and breakthrough seizures.¹²⁸

The link between AED and osteoporosis becomes more significant in the elderly.

Strategies

- *Future research into the extent of epilepsy and its impact in the elderly is required.*
- *Ensure that health professionals and carers involved in the care of the elderly are appropriately informed regarding epilepsy, its treatment and management.*
- *Seek additional funding to foster national collaboration between JECA and the aged care sector to develop a national aged care training program on epilepsy.*

Conclusion

This report is the first major step to giving people living with epilepsy in Australia a fair go. It highlights a number of recommended initiatives required to stop Australia from slipping behind other developed nations addressing epilepsy as a public health issue.

This report focuses on the need for national investment across research, workforce training, advocacy and community awareness programs.

This report focuses on the minimum level of activity required to afford people living with epilepsy the same level of care as those with other chronic conditions.

JECA recognises the constraints of the current economic climate and wishes to work with all Australian governments to better utilise existing resources, initiatives and government programs to improve the pathways and outcomes for people living with epilepsy.

JECA seeks to engage with governments, and the medical, health, welfare and disability sectors to enable systemic change in the delivery of services to people living with epilepsy.

Systemic change is necessary to ensure that people living with epilepsy enjoy a quality of life no less than that expected by majority of Australians.

Adoption of the recommendations contained in this report will not only begin this process but they present benefits, well beyond meeting statutory obligations, going to the heart of inclusion and equity for all Australians living with epilepsy.

Appendix 1.

Joint Epilepsy Council of Australia

The Joint Epilepsy Council of Australia (JECA) is the Australian Chapter of the International Bureau for Epilepsy (IBE) and consists of community-based organisations, which provide epilepsy services across Australia. The council works to address such social problems as education, employment, insurance, driving licence restrictions and public awareness.

In Australia, JECA provides a framework to ensure that various community epilepsy organisations have representation nationally, and internationally, and provides a mechanism for procuring resources for the movement and the exchange of ideas.

JECA members are as follows:

- Epilepsy Association (ACT) Inc
- Epilepsy Association of South Australia and Northern Territory
- Epilepsy Association of Tasmania
- Epilepsy Queensland
- Epilepsy Foundation of Victoria
- Epilepsy Association of Western Australia

Epilepsy Action (formerly Epilepsy Association of NSW) having withdrawn in 2008, has an open invitation and right to rejoin.

As individual organisations, each community group works to achieve the best possible outcomes for all Australians living with epilepsy and supports the Australian community by providing resources to ensure that informed decisions are made in relation to epilepsy.

As a network, JECA works towards achieving greater community understanding of epilepsy, by refocusing public attitudes and community attention to the realities of living with epilepsy in the Australian community.

JECA provides opportunities for its members to better tailor their service delivery around a broad range of social and health issues, including research and providing professional services in counselling, advocacy and social work for people living with epilepsy.

Epilepsy Society of Australia

The Epilepsy Society of Australia is a professional organisation for clinicians, scientists and technologists involved in the diagnosis, treatment and research of epilepsy in Australia. The purposes of the Society are to:

- Improve the medical care of people affected by epilepsy in Australia
- Foster a greater scientific understanding of all aspects of epilepsy through support of research
- Promote the exchange of medical and scientific information related to epilepsy

The Society grew out of the Austin Hospital epilepsy workshops which began in 1983, and has formed the Australian chapter of the International League Against Epilepsy (ILAE) since 1989. The ESA promotes and advocates improved medical management of epilepsy in Australia, enlisting financial support from various sources to fund scientific work within the field of epilepsy.

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