Submission to the

Senate Select Committee on Mental Health

THE EPILEPSY FOUNDATION

OF VICTORIA INCORPORATED

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The Victorian member of Epilepsy Australia **Australia's peak consumer-led epilepsy organisation**

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EXECUTIVE SUMMARY:

The relationship between mental illness and epilepsy is only poorly understood and continues to be a serious impediment to the well being of people living with epilepsy. In this submission we briefly outline how this has come to be so, we discuss some of the obstacles that exist, and we offer some possible solutions - to all of which we know we are well placed to contribute.

KEY CONCEPTS PRESENTED:

1. the loss of Victoria's epilepsy farm and colony was a major blow to treatment options today and highlights how hard it is to keep a clear and specific focus on epilepsy and not to simply bundle it in with general neurological conditions;

2. the unpredictability and episodic nature of epilepsy play a role in keeping epilepsy an illness that remains stigmatised and largely hidden;

3. some forms of epilepsy are associated with 25 times rate of suicide of the general population;

4. the relationship between epilepsy and mental illness is not straightforward and needs to be more thoroughly researched as does the fact that it is often mistaken for antisocial and even criminal behavior;

5. while there is general acknowledgement that epilepsy is far more than a medical condition, that it must be seen a social condition, this is not reflected in the treatment and management options made available to people living with epilepsy;

6. greater use should be made of accredited counsellors trained in solution focussed brief therapies [a Medibank rebate would be a good start];

7. about 300 Australians die annually from epilepsy making the need for a national audit of deaths in epilepsy a priority;

8. psychogenic seizures remain poorly treated in Australia;

9. fear, stigma, social marginalisation, depression, the often complex side effects from anti-epileptic medications, lack of access to neurologists, difficulties for carers and poor community understanding - are all impediments to effective epilepsy management.

10. it is vitally important for epilepsy to be part of any national examination of mental health.

REINTRODUCING EPILEPSY

In the dying decades of the nineteenth century, people with epilepsy were released from the walls of asylums to which they were often chained. The condition was seen less as madness or lunacy than as something involving the nervous system, and the importance of patients being otherwise normal during seizure free periods was increasingly acknowledged. Colonies and farms were often established, both in Australia and overseas, to provide safety, treatment and segregated support for people with recurring seizures - though these were generally only accessible to a limited number of those whose seizures were frequent and severe. In those countries where these facilities have been maintained they now make a valuable and highly successful contribution to people with intractable seizures who are able to attend them for re-evaluation, re-medication and epilepsy counselling.

Another major shift occurred in the middle of the twentieth century when a mistaken idea took hold that epilepsy had been effectively cured by the development of drugs such as phenytoin [*Dilantin*] and carbaomazapeim [*Tegretol*]. Nothing could have been further from the mark. The Talbot Epilepsy Colony and Farm was a victim of this thinking and its assets were confiscated by the Victorian government to make way for the building of Victoria's third university at Clayton - Monash University. The very fine Talbot Rehabilitation Centre that was then established at Kew but it offered remarkably little for epilepsy - and a half century of work by the epilepsy community was effectively flushed down the drain for political and medical expedience.

It took the efforts of new pioneers like Professor Peter Bladin at Melbourne's Austin Hospital to rekindle the medical interest in epileptology, and the work of families living with epilepsy to build the state and territory epilepsy associations that currently carry most of the social support role for Australians living with epilepsy.

NOT A MENTAL ILLNESS BUT A SIGNIFICANT MENTAL HEALTH ISSUE

While epilepsy has generally come to be understood as not being a mental illness, the relationship between epilepsy and mental health has remained blurred. It has come to be seen as a neurological condition and very little attempt to deal with it outside this framework is generally countenanced. Indeed a handful of outstanding neurologists fought long and hard to gain epilepsy its own clinical classifications, rather than allowing it to remain the symptom of other conditions where it is often present. This international work is ongoing while at the same time there is little being done to evaluate the possible contributions of epilepsy counsellors or social workers specializing in epilepsy.

The outward appearance of many seizures mimic many of the symptoms of mental illness - from intoxication to full blown madness - when in fact what is being seen is the body's response to a brief biochemical disturbance to brain cell activity. While scars, tumors and head injuries can be clear causes of epileptic activity, in most cases the cause of an individual's epilepsy remains as unknown as when the next episode is going to occur.

The unpredictable, episodic nature of epilepsy gives it a potential to be a highly threatening and destabilizing condition. It can introduce a climate of uncertainty and fear into a person's life and into the lives of those living with it. Most people with epilepsy present the same as anyone else between periods of seizure activity and many are determined that people never learn about their episodes when they are not like everyone else. Well meaning family members and health professionals who encourage people to keep their epilepsy secret are in fact acting as significant stigma coaches.

'It is doubtful if there is any other medical condition so universally neglected, due to a combination of social stigma, low profile and lack of resources.'
[WHO, ILAE, IBE., World Health Organisation Global Campaign against Epilepsy: Out of the Shadows, 1997]

There are a number of highly significant connections between epilepsy and mental health. They are generally poorly understood and sometimes controversial. What literature exists comes mainly from psychiatry, neuropsychiatry and neuropsychology, which further prejudices the treatment mindset of “professionals” and management options available to people living with epilepsy.

While we are keen that epilepsy not be seen as a mental illness - because to describe it as such is inaccurate - we need to acknowledge that mental illness can and does exist independently alongside a person’s epilepsy adding significantly to the burden of the condition, and that epilepsy can be a causative factor in the development of mental illness - even though this may be a slippery slope argument if it reinforces the often incorrectly held view that it generally leads to such an outcome.

EPILEPSY AND LIVING WITH EPILEPSY CAN PROVOKE MENTAL ILLNESS

Mental illness in epilepsy can be provoked by a variety of factors including the seizures themselves, the drugs used to treat them. as well as withdrawal from anticonvulsant drugs. It can be an unintended consequence of epilepsy surgery. It can arise from the isolation and stigma often associated with it [Shorvan et al, 2004] as well as from a vast range of other discriminatory social practices that serve to marginalise and destabilize the lives of people with epilepsy.

What follows are real life examples[1] which we hope will illustrate the kinds of mental health difficulties faced by people living with epilepsy and lend weight to the inclusion of epilepsy as a specific category or area for consideration, in any serious study of the mental well-being of Australians.

1. EPILEPSY CAN GIVES RISE TO BEHAVIORS THAT ARE TOO EASILY MISTAKEN FOR MENTAL ILLNESS AND CRIMINAL BEHAVIOR WHEN PEOPLE REMAIN IGNORANT OF EPILEPSY

The symptoms of seizures themselves can in fact mitigate strongly against mental well-being. For example, what are known as *simple partial seizures* can include a wide variety of such symptoms including anxiety, panic, irritation, hallucinations and even unusual beliefs, while *complex partial seizures* can manifest in temporary and often bizarre behaviors that can be seen to mimic mental illness and/or adverse reactions to alcohol or drugs. Failure to understand this regularly leads to disturbing levels of discrimination against people with epilepsy, from instances of them not being helped during a seizure, through to facing prosecution or other serious threats from community agencies.

A well-dressed middle aged man is having coffee at a café in a busy Melbourne street when he has a complex partial seizure. He proceeds to stand up and wander out of the coffee shop without paying. He is chased by both patrons and staff and restrained, in this altered state of consciousness. He tries to escape the people restraining him, the police arrive and he is arrested and charged with assault eventually leading to a

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[1] Each example offered is based on actual data gathered by the Epilepsy Foundation of Victoria. Significant identifiers have been altered in the interests of maintaining client confidentiality.

conviction. This has an incredibly negative impact on his already difficult struggle with depression.

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2. MENTAL HEALTH PROBLEMS CAN CO-EXIST INDEPENDENTLY OF A PERSON'S EPILEPSY.

Quite apart from any added mental and emotional difficulties caused by epilepsy, people with epilepsy are susceptible to and experience the common range of mental illnesses experienced in the rest of the community. This can be pose a further difficulty when people with epilepsy believe that their mental ill health is just a part of having epilepsy. One of the clearest examples of this occurs among some people who have undergone brain surgery to remove the cause of their seizures [an option not available to most people with epilepsy], when, although they have technically become seizure free, they nonetheless continue to demonstrate behaviors previously put down to having epilepsy.

Peter had brain surgery to remove his temporal lobe and the hippocampus beneath it, where his seizures were known to originate. He experienced a profound improvement in his seizure control and a year out from his operation is seizure free, though he has also remained on a monitored dose of anti-convulsant medication. His behavior is another matter altogether and has in fact worsened. He is prone to fits of temper and anger. He physically assaulted his mother in a supermarket, and has twice attempted suicide by slashing his wrists and arms.

He presents as a very pleasant, though garrulous, young man in his early thirties, who sees himself as an epileptic, and he talks about his surgery to almost anyone who will listen. He was living alone until his last self harm episode and is now living in supported accommodation but it is so far out of Melbourne that he has lost contact with many of the old friends who used to be comfortable with him.

It can also be the case that people "excuse" poor behaviors because somewhere along the way they have been told that their anger or inappropriate temper or other anti-social is not their fault but a consequence of being a person with epilepsy.

Graeme is in his fifties and has regular employment. He is very upfront about his epilepsy. He has had people from the Foundation out to his workplace on at least three occasions to explain epilepsy to his colleagues and sees that it is important for people to understand that while he has some special needs he is also just like everyone else. He has a rather dour disposition and can be quite confrontational - which he acknowledges can get him into hot water but he also expects people to understand that it is not his fault - after all he has epilepsy and it does that to people.

He is currently not seeing a counsellor as we expressed a view to him that it was not practical to come out to his workplace each year to give the same talk to essentially the same people and that we would rather help him to develop greater social skills. He feels let down and has given up on us.

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3. EPILEPSY, SUICIDE AND MORBIDITY

It is believed that people with epilepsy are at a much higher risk of committing suicide than the general population. For people with temporal lobe epilepsy the risk is 25 times greater and 5 times greater for those with severe epilepsy. [Hawton et al 1980]

There is an increasing awareness among people living with epilepsy that the condition itself can cause death. Though this is uncommon given the general number of people who have epilepsy in a community, it nonetheless represents around 150 Australians who each year will die from a seizure related condition known simply as SUDEP or Sudden Unexpected Death in Epilepsy. [“Sudden” because there seems to be no particular warning and “unexpected” because it is not in any way predictable from the nature of the seizures that the person has.] This matter gained global attention after a group of British parents managed to get an Adjournment Debate on the topic in the House of Commons. A Clinical Audit into Deaths in Epilepsy in the UK followed. There is however still great reluctance on the part of many physicians in Australia to talk with their patients about this matter and a level of resentment that epilepsy counsellors from epilepsy consumer groups do talk about it openly.

There is also the prospect of accidental death in epilepsy and the UK audit assessed this at around the same numerical level as it found for SUDEP.

While there has been a lot said by parents and partners of people who have died from epilepsy about their anger at not having been told of the possibility that death might be an outcome, there has been no systematic study of how the knowledge of this does impact on people living with epilepsy.

4 EPILEPSY AND DEPRESSION AND THE POSSIBILITY OF COUNSELLING

People with depression are more likely to develop epilepsy and people with epilepsy who are depressed have a poorer prognosis for seizure control through both anti-convulsant medication and surgery.

In a recent study comparing individuals with epilepsy to other chronic disorders like asthma, depression occurred in as many as 37% of the population, yet the vast majority had not discussed the problem with their physicians, putting this group at a much higher risk of other medical complications like stroke, diabetes and even high cholesterol. [Ettinger, A., Kanner, A. ,2005 ABC Radio]

Depression can often become a major issue for the people who live with and care for someone who has epilepsy and if left unaddressed they can experience deep feelings of guilt, anxiety and resentment often causing further problems such as divorce, abandonment and other forms of relationship breakdown

It is interesting too to note that when epilepsy and depression are written about, as indeed when mental health issues are generally addressed, there is usually always a reference to talking about it with ones doctor or getting a referral to a psychiatrist or neurologist. The vast community resource of trained and appropriately registered counsellors and social workers is routinely overlooked.

At the Epilepsy Foundation we have all of our staff [drawn largely from the professions of nursing, psychology, social work, education and counselling] complete at least one further formal qualification in solution focused brief therapy or solution oriented counselling. Increasingly, this kind of approach is being demonstrated to have an important place in the effective management of depression, anxiety and other emotional and mental difficulties.

We are increasingly convinced that once people feel they do not have to be overwhelmed by this unpredictable episodic condition, they can take concrete steps towards managing the impact it has upon them. The sooner they can actually start to regain control of their lives the better. Being in control of your life is not always the same as being in control of seizures - even though seizure control remains the first priority for almost [not quite] everyone diagnosed, and living, with epilepsy.

5. PSYCHOGENIC SEIZURES.

Many thousands of Australians have seizures that are emotionally triggered, Many thousands of Australians have seizures that are not actually epileptic in that there is no epileptiform EEG activity recorded during these episodes and the seizures themselves often demonstrate non-epileptic characteristics such as asymmetrical convulsive movements during what otherwise would present as a generalized tonic clonic seizure [where the convulsions are symmetrical in response to the whole brain activity involved].

Mary is an intelligent woman in her late forties who lives alone, is overweight, still entertains the idea that one day she will have children, suffers from poorly managed incontinence and at times has a very loud and aggressive manner .

She also has psychogenic seizures.

Mary has seizures in all kinds of places - very often requiring super efforts on the part of friends, ambulance officers and others to extract her and to provide help. No one has told her that her seizures are psychogenic though they are classically asymmetrical and she can be talked out of them in the early stages of onset. She can also come out of them in a matter of 5 to 10 minutes if she is offered food or other comfort. Her doctor continues to prescribe anti-epileptic medication which she takes in large quantities.

We have paid for Mary to have some time with a psychologist working on anger management and this seemed to help somewhat. The seizures became noticeably less frequent - though they didn’t stop. Helping her to move out of her feelings of being overwhelmed in the minutes that normally precede a seizure seems to work better than anything else. We really need to be able to teach her to consciously recognize her own ability to do this herself as well as to help her find other ways of managing the feelings of being overwhelmed and angry.

These kinds of seizures are sometimes referred to as non-epileptic attack disorder, pseudoseizures, non-epileptic seizures and psychogenic seizures. National data on this and strategies to help people who deal with them are all but non existent. Where medical doctors have attempted to find solutions to psychogenic seizures their approaches and conclusions about what can help have offered a number of possibilities though little agreement. Emeritus Professor Neil Buchanan from Sydney University has demonstrated that people with pseudoseizures, as he calls them, can be effectively taught to distinguish between their own epileptic seizures and any pseudoseizures they are having. Buchanan argues that this is a short process but one that involves a sound relationship between the patient and their treating doctor.

This view is disputed. Some medical practitioners believe that the same person will seldom actually experience both epileptic seizures and non-epileptic seizures. Others, such as the British neuropsychiatrist Tim Betts, believe that people can only learn to deal with these pseudoseizures if they can be placed in care for an extended period of some months and helped to work on a range of underlying issues that will eventually enable them to respond to stress and emotional difficulties more appropriately.

What we see, more often than you would expect, is people being treated with anti epileptic drugs which obviously have little or no effect, as they do not have epilepsy. We also see individuals being bounced from medical specialist to medical specialist - often with the label becoming more and more complex. In some cases there seems to be a genuine impasse where even specialists will express the view that people are beyond medical help - which in a sense is code for there being no available pharmaceutical solution. Seldom do these people get referred for counselling to a non-medical counsellor. Where it does happen it happens because people come to an organisation like the Epilepsy Foundation of Victoria where counsellors are employed and where no-one is turned away.

6. SOCIAL MARGINALIZATION

Here are two examples of how people with epilepsy can easily find themselves marginalised in their own communities.

Amanda is 28, single, unemployed, and frightened of losing her disability allowance though she would also like to have work. She has multiple seizure types, including drop attacks and tonic clonic convulsive seizures. She is only partly controlled by medication and is hopeful that one day she will be able to afford to have VNS [Vagal Nerve Stimulation] surgery.

She has had a lot of problems with public perception of her seizures. She has had both tonic clonic seizures and drop attacks, on the footpath, in stores or on public transport. People sometimes assume she is a "druggie" and have passed her by instead of calling for help and she will wake up with her head - or other part of her body - bleeding.

She always functions with some degree of depression which sometimes becomes quite severe as a result of how she is treated. Her response is to isolate herself and stay indoors, so she won't have to deal with public ignorance. Amanda has little money and very few material resources upon which she can draw in her daily struggle to be a part of the community. Her clothing is second hand, she has limited access to other people and the internet and her mobile telephone has only limited 'prepaid' use. For a long time she lived in a boarding house while waiting for public housing and the living conditions aggravated her seizures due to the high levels of stress she felt living among people with serious drug and alcohol addictions.

Due to a lack of family support, it is vital that she keep contact with her friends, to try to avoid the downward spiral into more depression that occurs when she isolates herself. She relies on the EFV a good deal for support and counselling, which is really one of the few things available to her that keeps her head above water.

Johan is 29 and was diagnosed with epilepsy when he was 26. He cannot control his seizures and feels that his doctors are not trying hard enough.

He is impatient with his efforts to gain control and is increasingly looking towards a religious solution. He lost in quick order his driving licence, his job, his fiancé and his financial security. He gets a limited taxi benefit which is almost enough to get him to the doctor when he has appointments in the city. He is frightened of public transport because he cannot predict his seizures.

There is a local group who volunteer with their own cars to transport people in his area on a regular basis but Johan is ineligible as he has epilepsy and epileptics are excluded as they may be incontinent during seizures.

Johan feels that he is in a prison in the outer suburbs of Melbourne but can not afford to move closer to the city. He can see no way back to his former life. His depression is worse after a seizure and he can feel very low for several days at a time. He is “grateful” that his seizures only happen every month or two.

The impact of living with epilepsy on the mental health of all those involved needs to be far better understood and articulated if we are to find better strategies and opportunities to enable people to cope with the incredible burden that this often brings.

SO WHAT IS IT THAT WE WANT?

While some epileptic behavior may look like or mimic classic stereotypic mental illness, we have worked hard to dispel the view that sees epilepsy as a mental illness and have also widely promoted the fact that most people with epilepsy are able to gain total control of seizures within two years of onset and will indeed lead perfectly ordinary lives. In our efforts to educate people about this we have often overlooked the connections that do exist between epilepsy and mental health and have almost certainly done a disservice to those people who are dealing with a mental illness as well as epilepsy. Each of the following priority actions go some of the way towards our community gaining a more realistic grasp on the realities of epilepsy and mental illness.

1. Information and education for law enforcement officers to include specific information on how to recognize a person having a seizure and to act appropriately.

2. Information and education on epilepsy to be provided for all people whose work places other people in their care such as teachers, taxi drivers, prison officer, hairdressers, restaurateurs and so forth.

3. The inclusion of epilepsy as a specific condition requiring specific consideration in any mapping or collection of national data on depression, suicide and mental illness.

4. A greater knowledge base and awareness of the costs of stigma and marginalization to individuals and families living with epilepsy and the personal and social framework needed to work towards appropriate solutions.

5. Specific funding for programs which enable people living with epilepsy to share insights and strategies for coping with the real burdens they face on a daily basis.

6. Specific counselling support programs for people with psychogenic seizures.

7. A closer look at the impact of deaths in epilepsy among those living with epilepsy.

8. An appropriate examination of the impact of epilepsy on other conditions such as acquired brain injury and in particular of its impact on the normal development of children who have it as part of a multiple disability, and their recourse to appropriate counselling and self management support.

AN EXPLANATORY FOOTNOTE . . .

Epilepsy is arguably the most serious health condition affecting the brain in the world today and has a long history of being sidelined, and all too often, ignored. The figure generally offered for its prevalence in the community is 1% of the population with a cumulative prevalence figure of around 3% to age 70. Its incidence among older people seems to be dramatically increasing. [*See figures below*]

Despite being relatively common [we estimate that at least 10% of the community have, live with or deal with epilepsy on a regular basis] it remains in many ways a hidden condition . . . and its importance in Australia as a mental health issue is clearly not well addressed.

As a physiological condition epilepsy all too often lurks in health data under related headings such as malignant brain neoplasms, benign brain tumors, cerebral palsy, alcoholism, stroke, acquired brain injury and so on. Much health data in Australia pointedly ignores epilepsy as a condition altogether., or minimizes its impact. Health resourcing in Australia sadly reflects this.

The head in the sand attitude that prevails towards epilepsy has many dangerous consequences, so much so that the US Centre for Disease Control and Prevention has very recently launched a major initiative to educate people about epilepsy, so that it can be more readily identified and brought to treatment. Despite its low profile, epilepsy is probably one of the fastest growing of all conditions with reports that as many as 1 in 10 patients in US nursing homes are now on antiepileptic medication and as many as 7.5% of people over 75 are likely to experience some kind of epilepsy.

But this is not new. In 1993 a study was commissioned by the World Health Organisation and undertaken by the World Bank to look at how around 100 diseases and injuries impacted on the loss of a healthy life. Conditions were rated using the scale known as the Global Burden of Disease [GBD] expressing the impact of health conditions in what are called Disability Adjusted Life Years [DALY's]. [World Development Report 1993 - Investing in Health, published for the World Bank by Oxford University Press, New York, 1993]

For women the burden of epilepsy was rated on a par with breast cancer and diabetes, more than twice the burden of leukaemia, three times the burden of lymphoma and about six times the burden of the neurological conditions of both multiple sclerosis and Parkinson's disease.

For men, epilepsy is on a par with cancer of the trachea, bronchus and lungs, almost twice the burden of diabetes, four times the burden of prostate cancer, 8 times the burden of multiple sclerosis and 10 times the burden of Parkinson's disease

While epilepsy is a medical condition it has, arguably been too medicalised, leaving the many psycho-social and political issues to which it gives rise at best poorly understood and at worst largely ignored.