

Epilepsy Report

Focussing on better community and health outcomes for people living with epilepsy.

Issue No. 1, 2011

Purple Day! *Australia celebrates*

Review

2nd Dravet Syndrome Family Conference

Professor

Harry McConnell

Epilepsy & behaviour

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Reachelle Beasley

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developing novel AEDs



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changed his life**

WELCOME

Welcome to the latest edition of *The Epilepsy Report*.

The 8th Asian and Oceanian Epilepsy Congress held in Melbourne was a great success with record attendance at the *Epilepsy & Society Symposium*. The international and local speakers mingled with delegates during the breaks providing unique opportunities for further discussion. Delegates were delighted to have the chance to speak to Dr Elson So, Professor Graham Scambler and of course, Wally Lewis and Marion Clignet.

On March 26, Epilepsy Australia celebrated Purple Day for Epilepsy Awareness. This awareness campaign was extremely successful across the country with all television stations running our Purple Day Epilepsy Awareness community service announcements, great coverage in the print media in each state and our website taking record hits during the month of March. Cassidy's simple message – wear purple for epilepsy – really caught on. Thousands of students took up our challenge to 'go purple for epilepsy' learning more about epilepsy and what to do if they saw someone having a seizure while donating funds to support our work.

Our Purple Day Heroes spread the message far and wide via social networks facebook and twitter, while supporters in every state raised awareness by selling purple day merchandise and holding their own awareness events at home or at work. Companies held BBQs, purple cupcakes and muffins were baked, pharmacies went 'purple' and shop windows were dressed, even jockeys wore purple arm bands supporting our cause.

Planning for Purple Day 2012 is already underway and is promising to be an even greater success.

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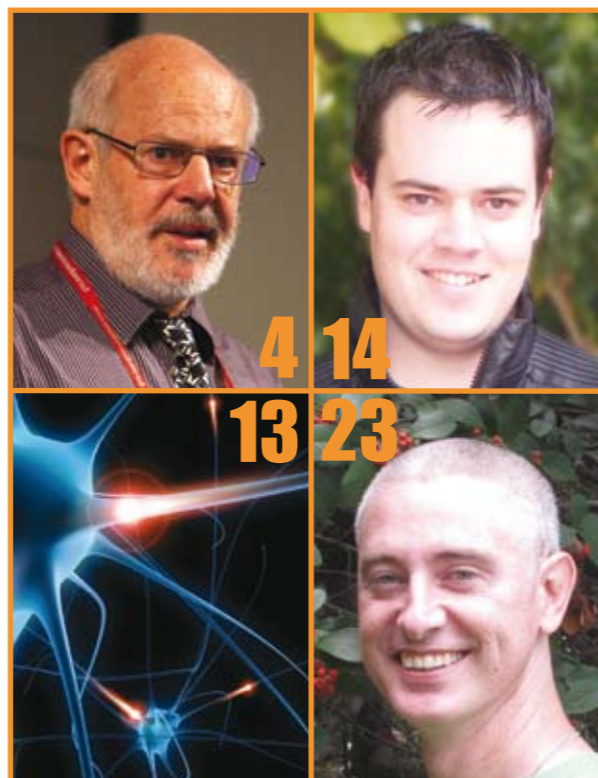
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Highlights from Melbourne congress

Epilepsy & Society symposium a great success

This symposium was a highlight of the congress attended by a record 234 delegates from across the region. Excellent presentations from international speakers Graham Scambler of the University of London and Olympic cyclist Marion Clignet, along with our own Wally Lewis who spoke candidly of his own experience with epilepsy spanning more than 20 years, were well received.

Delegates enjoyed the opportunity to chat with Wally during the morning tea break, have that special photo taken, or have a copy of his book signed with a personal message.

The discussion groups that followed examined a variety of epilepsy-related issues including sexuality; memory; sport and exercise; practical ways to manage depression; employment and advocacy issues; sudden unexpected death in epilepsy (SUDEP); and epilepsy and creativity. The interactive sessions were lively with the presenters making themselves available to continue to answer questions during the breaks.

The day concluded with the presentation of the *Outstanding Persons with Epilepsy Awards* by IBE President Mike Glynn.

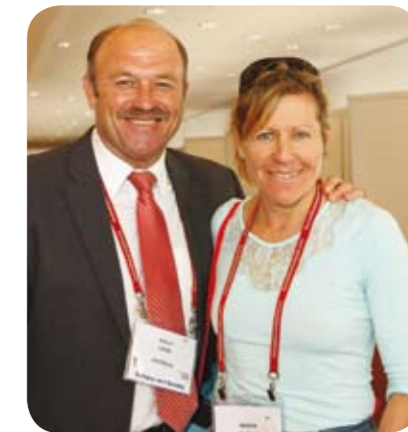
Promising strategies showcased

Since its creation in 2005, the Promising Strategies program of IBE has supported more than 30 projects around the world. In Melbourne, a poster display showcased the projects in the South East Asia and Western Pacific regions funded since the program was introduced.

This was enhanced by an exhibition of the craftwork created by the Seahorse Club in Shanghai, which received funding to create an artists' studio in the last round of funding. The exhibition included framed pictures, beadwork, calligraphy and clothwork created by people with epilepsy who are supported by the club in Shanghai.

Creative Sparks Art Exhibition

An exhibition of 50 international and local artists with epilepsy, curated by Jim Chambliss, was an added dimension to this congress. As an adjunct to Jim's presentation *The influences of epilepsy in visual art*, the on-site collection and computer access to the online creative sparks exhibition at www.artandepilepsy.com, provided delegates with the opportunity to explore the relationship between epilepsy and creativity.



Wally Lewis and Marion Clignet

Epilepsy practitioners meet in Melbourne

With epilepsy support workers travelling to Melbourne to attend the 8th AOEC, the Epilepsy Foundation of Victoria hosted a Service Practitioners Forum immediately before the start of the congress.

The aim of the meeting was to get an understanding of how each epilepsy organisation supports people with epilepsy; to build networks between epilepsy workers; to share ideas, new resources, innovative practices and knowledge; and to identify some share priorities on how we can work together to get better outcomes for people living with epilepsy throughout Australia and New Zealand.

Forty four staff members from Australian epilepsy associations, Epilepsy New Zealand, and Epilepsy Bereaved (UK) attended the forum. It was agreed to examine regular networking opportunities throughout the region.



Epilepsy Practitioners Forum, Melbourne



The Stigma of Epilepsy and its Impact

Graham Scambler, Professor of Medical Sociology, University College London, UK

Negative connotations of epilepsy have a long if varied history. In this short contribution I shall address: (1) the extent to which this diagnosis or 'label' continues to elicit feelings of shame and to provoke discrimination, and (2) how best to understand the relative importance of (1) for the quality of life of people with epilepsy. It is an account that I initially brought with me to share with conference participants in Melbourne and then Brisbane in the autumn of 2010, but also one that has been modified as a result of the numerous conversations I enjoyed with hosts, colleagues, people with epilepsy, and advocates.

In a book published over 20 years ago (Scambler, 1989), I advanced what I called a 'hidden distress model of epilepsy'. Perhaps oddly, it is a model that still seems to capture something of the experience of living with epilepsy, notwithstanding the sheer heterogeneity of symptoms that comprise epilepsy and of pathologies of which it is a manifestation. At the core of the hidden distress model was the unexpected 'finding' that a sense of personal shame and anticipation of rejection ('felt stigma') trumps actual instances of discrimination ('enacted stigma') as far as epilepsy's impact on quality of life over the life-course is concerned. This warrants a few sentences of elaboration. When adults are informed they have epilepsy, it seems they often become defensive: they fear the worst. It is a label they see as threatening to their wellbeing, whether at the hands

of partners or employers or via those casual interactions that somehow or other make for a contented life. Children have none of these reservation of course, but they can and frequently are 'coached' towards felt stigma ('don't use the word 'epilepsy' at school', 'your granny doesn't like the word', 'no need to tell your boss', 'why invite trouble?') (Schneider & Conrad, (1993)). This defensive orientation discourages openness. The word 'epilepsy', even the fact of turns, blackouts, seizures, remain personal or family secrets. One product of this secrecy is a low rate of enacted stigma: how can people discriminate if they are not 'in the know'? So this is the route to felt stigma's toxicity. Moreover Jacoby (2002) has shown that felt stigma – and the hidden distress model – retain their salience even when people with epilepsy are in remission or have a low rate of seizure frequency. Labeling, and self-labeling, can disrupt people's lives more than the symptoms that get the whole process underway.

In October 2010 in Melbourne, I shared a platform at the Asian and Oceanic Epilepsy Congress with an Australian sporting superstar, Wally Lewis (2009), whose exploits were unknown to me (I follow rugby union), but whose renown became clear to me as all eyes fastened on him. He recounted his personal experiences with great eloquence, and they too seemed consistent with the hidden distress model. Accommodating seizures towards the tail end of his playing career, he kept his own counsel, reasoning that any indication of 'weakness' could tell against him one way or another. On retiring from the game, and now in receipt of a diagnosis of epilepsy, he again opted for secrecy in his new job as a television sports presenter. Felt stigma seemed to underpin this resolute preference for non-disclosure: he feared the worst, dismissal, should

his 'secret' leak out. When the scenario he most dreaded – a seizure on live TV – occurred, like many in my own sample, he was surprised and relieved to find those around him empathic and supportive rather than aggressively defensive. Given his public profile, Wally Lewis' willingness to share this 'experiential' rather than 'scientific' knowledge is powerful indeed.

As a sociologist it would perhaps be understandable if I limited myself to a discussion of how social phenomena – like stigma – can impact negatively on the biographies of people with epileptic seizures. After all, this is where any expertise I possess begins and ends. But I want to take cognizance of the fact that biological and psychological mechanisms are active at the same time as social mechanisms (and 'biological' and 'psychological' are of course forms of shorthand, since multiple subdivisions are possible). For any given individual, epilepsy-related quality of life depends on a variable mix of the biological, psychological and social. Epilepsy is a symptom not a condition. If the underlying pathology is severe, with seizures but one manifestation, then epilepsy per se might be quite unimportant for quality of life. In the absence of overwhelming pathology, psychological factors like personality or locus of control might be critical. If the epilepsy is mild, then psychological or social factors are likely to be key. I have suggested that if any generalization is possible, biological mechanisms typically matter, psychological mechanisms condition people's coping, and social mechanisms provide what can be critical contexts (Scambler et al, 2010).

I will now focus more on social mechanisms, or contexts. One neglected possibility, less rare than we might think, is that epilepsy can impact negatively on quality of life in the

absence of biological mechanisms. How can this be? It can occur when epilepsy is misdiagnosed. The conferment of the diagnostic label by a state-licensed authority like a physician turns a person-cum-patient into 'an epileptic', as it were, like it or not. By the same token, the presence of the requisite mechanisms need not lead to medical, social and self-labeling if a physician is not consulted or there is a failure to diagnose: what is lost here in terms of antiepileptic treatment might be compensated for by the lack of a potentially stigmatizing label and status.

There are a number of ways in which social mechanisms are relevant to the study of epilepsy and to epilepsy-related quality of life. First, the medical diagnosis of epilepsy is itself more recent than many imagine; and the phenomena sheltering under this diagnostic umbrella, and their division into types and sub-types, continues to be re-assessed. The evolution of diagnostic categories and their modes of application, in other words, are themselves worthy of sociological investigation. Science and medicine in both pure and applied forms are 'social constructed', that is, products of particular times, places and configurations, as are all branches of knowledge. To state this is not of course to denigrate them in any way, as is sometimes suspected.

A second sociological focus is aetiology. Just how might social mechanisms contribute to those pathologies of which epilepsy is a manifestation? It is apparent, for example, that those from low-income families are more likely than those from high-income families to suffer accidents in the home, neighbourhood and workplace (perhaps a function of deprivation); and that men are more likely to have accidents than women (perhaps a function of differences in patterns of behaviour). It is likely therefore that epilepsy, along with most other conditions/symptoms, is to be disproportionately found in specific social segments or groupings.

Behaviour around symptoms is a third area of enquiry. Why is it that some people report and seek help for seizures while others do not? Interestingly, it might be extrapolated from the sociology of health, illness and help-seeking behaviour that people from lower-income families and men are prone to be 'poor' help-seekers. Help-seeking

does not always imply professional or medical help however. The anthropologist Kleinman (1982) writes of 'local health care systems', distinguishing between 'popular', 'folk' and 'professional' sectors. It is easy in developed societies like Australia and the UK to exaggerate the salience of the professional sector. We know little about the ways in which people handle their symptoms in the 'privacy' of their personal or close-knit family or other networks, or with the engagement of complementary or alternative practitioners.

A fourth dynamic is that between physician/healer and patient/client. It is known that attributes of these relationships can have a direct bearing on the effectiveness or otherwise of treatments and on quality of life. Over 20 years ago I suggested that 'good quality medical care' implied more than efficient tests, diagnosis and seizure management. I referred to the need for 'co-participation in care', affording patient autonomy; for an 'open agenda' during consultations, allowing patients to ask questions and raise their own concerns; for a holistic rather than biomedical orientation to care; and for physicians and other health workers to be trained in counseling. I stressed that if physicians protested that they simply did not have time to respond to such criteria, then this may be reasonable, but that nobody should conflate 'the best one can do in the circumstances in which one finds oneself' with 'good quality care'.

A fifth focus is on coping, a focus that underpinned my own early studies. The hidden distress model of epilepsy belongs here. There is in fact now a considerable literature on the pros and cons of day-to-day living with chronic conditions (or symptoms), including a range of studies on the impact of enacted and felt stigma on the biographies of people with epilepsy.

Finally, sociology might contribute more than it has so far to the investigation of how stigma, invoking norms of shame, has come to take its present forms. An emphasis on coping suggests we are dealing with a 'personal tragedy' when epilepsy is diagnosed. Disability theorists and activists have insisted instead that norms of shame constitute a form of oppression. So why is it that epilepsy remains stigmatizing (and 'dis-abling') in countries like Australia and the UK?

To what extent are norms of shame embedded in deep social structures that are resistant to purposive change?

These six foci add up to an extensive research programme, and one which, although well underway, requires deepening as well as extending. A great deal more money is spent on studying biological and even psychological mechanisms in relation to epilepsy than their social equivalents. Nor does what we know so far translate easily into interventions to reduce stigma. I have suggested elsewhere, however, that a reasonable starting point is a recognition that felt stigma is a key component of the disadvantages that can accrue to people with epilepsy. Adopting Bourdieu's (1977) idea of habitus (i.e. a socially acquired mind-set that predisposes us to think and behave in certain ways), it is important to discourage people with epilepsy from adopting an 'epilepsy habitus'. Adoption of an 'epilepsy habitus' would seem to preclude what I have recently called 'project stigma'. This denotes to a refusal to accept enacted stigma without falling prey to felt stigma: it is the kind of 'fighting back' epitomized in the activities of Wally Lewis and many, many others.

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Presentations from the Epilepsy & Society Day are available at www.epilepsyaustralia.net/Presentations/Conference_papers.aspx

Memory – A marvel of nature

Dr David Weintrob

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As with walking and breathing, we often take our memory for granted and barely spend time marvelling at the astounding evolutionary feat it represents. I have three aims in this talk: (1) to remind you of the marvel that is memory; (2) to take you on a brief journey through the recent history of memory research and to outline the vital contribution that people with epilepsy have made to our modern understanding of how the brain makes memory possible, and; (3) to leave you with a sense of the nature and cause of memory dysfunction in epilepsy. That is, what are the kinds of things people with epilepsy forget and why.

At the outset, we need to understand what memory is. For most of us, it reflects the ability to remember an event that occurred in the past. Our 21st. Our marriage. The birth of our child. And, indeed, this is how memory is often defined by respected dictionaries. For those who study memory, however, memory is a much more diffuse, and indeed nebulous, phenomenon.

In general, for the neuroscientist, memory reflects the capacity of the organism to benefit from experience. It is, therefore, a ubiquitous presence in many very different life forms and assumes many different guises. For example, the ability of the earthworm to habituate to its environment represents a legitimate memory. So too is a dog's conditioned salivation in response to a bell.

In humans, memory ranges from simple ("his name is David") to complex ("she can recite all Shakespeare's sonnets"), from highly specific ("The talk starts at 11am") to the most general ("A lion is a kind of animal"), from the trifling ("I need to buy milk") to the vitally important ("which button launches the nuclear missile?"), from the visual (face recognition/painting recognition) to verbal (remembering a poem) to the spatial ("How do I get ... there?") to the musical ("I can hum 20 different Beatles songs") to the active (I can kick a football without even thinking about it). It underpins our ability to ride

a bike, obey traffic signals, identify objects by name, use language, and behave appropriately when in church.

Moreover, and perhaps even more astoundingly, it encompasses the ability to be consciously aware now of an event that occurred seconds-minutes-hours-years-decades ago, and to re-experience that event – even if it occurred decades ago – with a vitality and full reawakening of the colors, textures, and emotions we felt at the time ... and to recall when and where the event occurred.

In that it underpins our personal autobiographies, memory is integral to personal identity. That is, it is integral to our sense of who we are.

Note too, that a special kind of consciousness accompanies memory. When we recall events from our past, our conscious awareness of that experience is different from our ordinary 'online' awareness of our environment. We seldom confuse the feeling that we are remembering an event with the feeling that we are admiring a sunset, dreaming, solving a Sudoku problem, or wondering what we should have for lunch. We are certainly conscious while doing those activities, but that consciousness is plainly and recognizably different. Endel Tulving, one of the doyens of memory research, has used the term "autonoesis" to refer to the special kind of consciousness that allows us to be aware of the subjective time in which events occurred.

Paradoxically, therefore, not only does memory allow us to travel back in time, it allows us to recollect future arrangements and to project ourselves into the future. That is, it seems to be closely linked with our ability to perceive the present moment as a continuation of preceding events and as a prelude to future activities. This last ability is probably unique to humans and is a vital precondition for human cultural evolution – awareness of the existence of a past is a necessary precondition for changing the future.

Memory is truly a remarkable evolutionary achievement.

The complexity of memory: refining the question

In all its variety and glory, memory is being investigated across many different species, at many levels of analysis (molecular – cellular – anatomical – cognitive), using many different and often highly sophisticated techniques. Novel findings are reported almost daily in journals devoted solely to memory research. Any literature search will yield literally tens of thousands of studies.

What is indisputable is that memory did not evolve for the convenience of the neuroscientist. While significant progress has been made, Endel Tulving – one of the doyens of memory research – has noted rather prosaically that the main finding is that memory is "extraordinarily complicated".

Epilepsy and memory

Nonetheless, the study of memory in people with epilepsy, and temporal lobe epilepsy in particular, has been enormously influential in attempts to impose scientific order on this amazing ability. It has also played a vital role in helping us understand how the brain makes memory possible. This is because in TLE, epilepsy and memory co-habit the same space. Indeed, Snyder has commented that the study of memory in individuals with temporal lobe epilepsy has provided "the most singularly important natural laboratory for uncovering the neuroanatomic bases of human memory." (Snyder, 1997). The remarkable patient H.M. is regarded as the index case and our story really starts with him.

H.M.

After being introduced to the medical world in 1957, H.M. went on to become one of the most studied of all patients in medical and psychological history. In 1953, aged 27, H.M. underwent surgery in Canada to relieve his severely disabling epilepsy. In what his surgeon described as a "frankly experimental procedure", H.M. had the front-most end of both his temporal lobes removed. H.M.'s epilepsy was substantially improved by this operation.

However, it soon became apparent that he'd sustained a "striking and totally unexpected" disturbance of memory. By way of illustration, he would re-read the same newspaper or magazine several times, seemingly unaware that he'd done so before; he was unable to remember the names of any doctor he met after his surgery, nor could he recognise them as familiar from one day to the next; if he left his room he was immediately lost.

In 1996, over forty years after his operation, the enduring severity of H.M.'s memory impairment was described by the New Zealand neuropsychologist Jenny Ogden as follows:

"He does not recognise anyone he has met or seen since 1953 and cannot even recognise current photographs of himself. He cannot say what he was doing 5 minutes ago; with whom he lives; what day, month, year, or season it is; or his age."

And, by the way, just as a quick mental exercise, contrast that with your own memory for all the myriad episodes that you can remember from just this morning (e.g., from waking up, to making breakfast, to driving to work, to walking into this building etc.

Tragically, after his surgery, H.M. was locked into a permanent present that he described as "like waking from a dream...everyday is alone in itself"; in Ogden's words, he was "marooned in the moment."

The hippocampus

Intriguingly, however, H.M.'s difficulties were "curiously specific to the domain of recent memory". His intellect, his personality, his ability to negotiate the niceties of social interaction, and his ability to speak and use language were all unchanged. This observation laid the basis for a critical insight, namely, that memory could be dissociated from other cognitive and behavioural domains. Critically, this in turn suggested the existence of a brain region whose principal function is memory formation.

Comparing H.M.'s operation and memory disturbance with other patients who'd had comparable, albeit less extensive, resections, logic dictated that the hippocampus was a critical structure. That hypothesis was subsequently confirmed and today the hippocampus is recognised as a critical component of

the memory system, even if its precise role remains a subject of intense debate. The centrality of the hippocampus to memory is why temporal lobe epilepsy, which is often associated with damage to the hippocampus, has played such a central role in memory research.

Multiple memory systems

However, there was one other critical observation. Although H.M. was unable to retain any memory for the activities he'd personally undertaken minutes-hours-days beforehand, he was nonetheless capable of some learning. For instance, he could retain in mind a string of numbers, such as telephone number, and accurately recite them back to the examiner; he was capable of learning new motor skills, even though he was unable to recall doing the task before. Priming was also intact – e.g., if H.M. was shown a word such as 'DEFINE' and was later given the stem 'DEF' and asked to complete it with the first word that came to mind, he usually responded with the word shown earlier. If asked whether he'd seen the word 'DEFINE' beforehand, however, he'd deny any such memory. Similarly, with repeated exposure, he became faster at recognising incomplete line drawings even though he had no memory for seeing the drawing previously.

These observations underpinned a major insight, namely that memory is not a single, monolithic structure – instead, memory represents a range of different learning systems reliant on different parts of the brain.

Declarative versus non-declarative memory

In this model, a distinction is drawn between declarative and non-declarative forms of memory.

Declarative memory is concerned with memory for specific facts, i.e., with "knowing what". It is so called because one can bring to consciousness and declare the content of this memory. That is, we are able to think about these sorts of memories, talk about them, and manipulate them in the spotlight of full awareness that it is a 'memory'. It allows us to declare, for example, that on my 21st birthday we had a beach party and that my brother made an embarrassing speech. Or, it allows me to declare that I remember that the chemical formula for salt is NaCl. This knowledge can be used flexibly across different situations. The

declarative memory system is capable of rapid, one-trial learning. It is severely impaired in H.M. and other cases with bilateral hippocampal damage. In contrast, non-declarative memory is spared.

Non-declarative memory refers to memory for skills or procedures, i.e., it is concerned with "knowing how". For example, the skill needed to ride a bike represents one kind of non-declarative memory – as we all improve our bike riding prowess over time some form of memory must be involved. However, this kind of skill memory cannot be "declared" – rather memory output is manifest by performance of the skill. Similarly, the ability to read a friend's handwriting because we have encountered it several times in the past is an example of non-declarative memory. Priming and the formation of habits and emotional predispositions are other examples. This sort of memory cannot be used flexibly – rather it is a memory of sorts that can only be utilised under very particular conditions that very closely resemble the original learning episode. Most often, multiple exposures to the stimulus are required for this sort of memory to develop slowly and incrementally.

Declarative memory is further divided into 2 systems:

1. *Episodic memory*, i.e., memory for specific, personally-experienced events located in space and time. This system forms memories that are unique to the individual, define individual life histories, and ultimately contribute to the sense of self. These sorts of memories are inextricably bound up with a specific time, place, and emotional state in the individual's life history. Collectively, the amalgam of this information constitutes a memory episode. For example, being able to recall that last summer on the first night of my vacation in Bali I met a retired ship's captain over dinner whose company was very enjoyable is a form of episodic memory. It provides, in other words, an autobiographical framework that permits recollection of personally-experienced activities and the time and context in which they occurred. This is what most of us mean by memory – so too did the famous philosopher William James who wrote "Memory requires more than mere dating of the fact in the past. It must be dated in my past";

2. *Semantic memory*, i.e., memory for facts or general information about the world. It is impersonal, i.e., the content of this kind of memory is not specific to the individual but may be shared by literally billions of people. Moreover, it contains no record of the context in which the memory was formed. It encompasses, for example, our knowledge of the meaning of the word ‘testify’, the usual colour of a banana, the taste of an apple, the chemical formula for table salt, the knowledge that the summer months in Brisbane are usually quite humid, and how to behave when you enter a restaurant. Billions of people know and can declare this kind of memory without remembering the occasion on which it was learned.

To reinforce the distinction: Being able to state that Princess Diana died in Paris in a car accident reflects semantic memory; being able to state that one was eating breakfast at 7am in the kitchen and that you felt very sad when you learned this from the TV news broadcast reflects episodic memory.

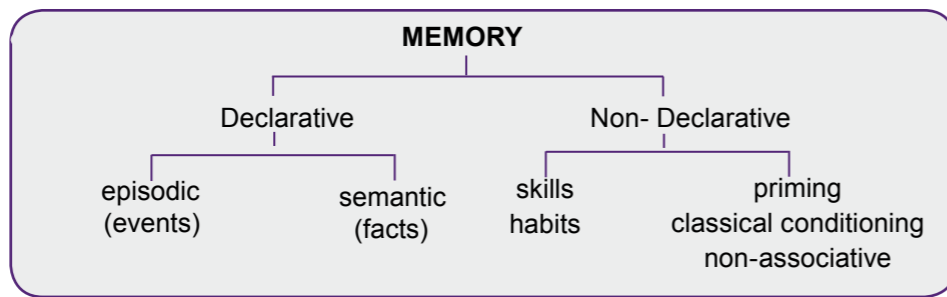
An evolutionary aside

Semantic memory is the kind of memory that makes it possible for organisms to store a kind of “general knowledge” of the world and then use this information flexibly and appropriately. All kinds of animals have excellent semantic memory – that is, they know a lot about the kind of world they live in. Our evolutionary ancestors were like this, but at some point in human evolution, possibly rather recently, episodic memory emerged as an embellishment of semantic memory. As far as we know, no species other than humans has episodic memory of the kind just described. That is, no other species has any subjective sense of self as existing in time with the ability to re-experience discrete events in one’s personal history.

H.M. revisited

In respect of Temporal Lobe Epilepsy (TLE), it is really declarative memory we’re concerned with. More specifically, and particularly in light of its significance for everyday life, it is episodic memory that is usually of most concern to neuropsychologists and people with TLE.

As we’ve seen, episodic memory was profoundly impaired in H.M. After nearly 40 years he could recollect few, if



any, events he’d personally experienced since his operation. Fortunately, however, unlike H.M., the overwhelming majority of people with TLE have damage confined to one temporal lobe. Consequently, any accompanying memory impairment tends to be very much milder than that of H.M.’s.

This is not to downplay the significance of memory impairment for patients and family, but fortunately we don’t see the dense, disabling gaps in memory for recent personal activities that H.M exhibited. Having said as much, however, what kinds of memory difficulties do patients with TLE typically experience?

The nature of forgetting in TLE

The paradox of H.M. is that through him we have learned a great deal about human memory, but because of the unexpected tragic results of his surgery the sample size of one will never increase. That is, no one has ever attempted removal of both temporal lobes again.

Following H.M., however, attention turned to patients with epilepsy who’d undergone unilateral resections of one temporal lobe only. These patients also showed memory impairments, albeit very much milder than that of H.M. Moreover, the nature of the deficit varied as a function of side, with memory for verbal information, i.e., information conveyed through the medium of language, being most affected by surgery on the left temporal lobe and memory for non-verbal information, i.e., information with a prominent visual or spatial emphasis that is not easily represented in language, being affected by surgery on the right temporal lobe. For example, the ability to learn a list of 15 words was depressed in people who’d undergone a left temporal lobectomy, but normal in those who’d had a right-sided operation. In contrast, the ability to remember an abstract geometric figure was depressed in people who’d had a right temporal lobectomy, but normal in

those who’d had a left-sided operation.

Subsequent studies showed that, even prior to any temporal lobe surgery, similar problems affected people with either left or right temporal lobe epilepsy. These observations led to the material-specific model of memory, a theoretical framework which, although questioned in more recent times, still guides practice in many epilepsy centres around the world.

To summarise: Unlike H.M., people with unilateral TLE retain the ability to lay down personal memories and therefore generally retain an ongoing and coherent autobiographical record. Against this backdrop, however, the individual with unilateral TLE may well have difficulty remembering the fine details of events they experience and new information they encounter. This is most pronounced for verbal information when the left temporal lobe is involved and most pronounced for non-verbal (i.e., visual and spatial information) when the right is involved.

Thus far, I’ve been referring to memory as it applies to a person’s performance on a standardised, objective test of memory. That is, I’ve been referring to their performance on tasks that require them, for example, to learn a list of words or memorise an abstract figure. Relatively little work has been done attempting to understand how memory impairment on testing translates into deficits in everyday life. As broad pass, however, the kinds of things people with temporal lobe epilepsy tend to struggle with include:

Left temporal lobe epilepsy and hippocampal damage: retrieve skeletal autobiographical memories for which the gist of the memory is maintained, but some of the specific details are lost (St-Laurent et al, 2010; Thaiss and Petrides, 2008); they may remember having the conversation, but find that their memory for the details of what was spoken about is unreliable; details of instructions; details of information read in books and newspapers.

Right temporal lobe epilepsy: memory complaint less frequent; route around the city centre or local shopping centre; the layout of their local supermarket; location of their car on leaving the supermarket; less often, facial recognition

In both, there may be a denser and more encompassing disruption of memory for events that occurred shortly before or after a seizure.

TLE, memory, and some general observations

At this point, I will briefly canvass a few other pertinent issues:

Severity – what determines the severity of memory impairment in TLE? Earlier age at onset of seizures, longer duration of epilepsy, and greater seizure frequency tends to be associated with a somewhat more severe impairment of memory (although exceptions are seen, raising the possibility that in some patients memory has transferred to the other temporal lobe);

Memory decline after temporal lobectomy – this issue is always taken extremely seriously and is always very carefully considered. The first point to note is that for most people with right TLE, a right Anterior Temporal Lobectomy (ALT) does not cause any discernible change in memory on specific testing. However, given that the left hemisphere of the brain is typically dominant for language, and given that most of what we need to remember is embedded in language, left ATL is usually much more of a concern. Again, however, as a general principle the damage, so to speak, is often done by the time a left ATL is contemplated and removing a part of the temporal lobe does not place people at great risk of a further disabling decline in memory. A recent study (Williams, Martin, & McGlone, 2009) looking at the subjective experience of memory change after surgery found that most patients denied any significant change in their memory after temporal lobe surgery. Indeed, a small number of patients report (Williams, Martin, & McGlone, 2009) and exhibit (Baxendale et al, 2008) a modest improvement in memory. This converges on our experience at Austin Health.

In a small number of patients, however, the possibility of a significant change in verbal memory does exist. This is true especially of people with

late-onset left TLE, no or only very mild hippocampal pathology, or normal or only mildly impaired verbal memory beforehand. The guiding philosophy in our program is that this needn’t rule out surgery. Rather, any risk to memory needs to be weighed against the benefits of seizure freedom and, moreover, needs to be understood in terms of what the likely functional consequences of memory decline will be. That is, although we might expect to see a change for the worse on our memory measures, this doesn’t automatically translate into difficulties in everyday life. For example, a QC who relies very heavily on verbal memory might be a different prospect to someone with a more routine or repetitive occupation, even if the decline seen on our tests is equivalent.

Decline with time – there is evidence that refractory TLE may be associated with a slow but progressive decline in cognitive abilities (e.g., Jokeit & Ebner, 2002; Hermann et al, 2002; Cascino, 2009). That is, poorly controlled seizures may cause cumulative cognitive deficits over time. There is, therefore, a growing belief that epilepsy surgery may not be a procedure of last resort in suitable candidates. Time may mean neurons.

Immediate, short-term, working, and long term memory

Up until now, we have considered memory in terms of the nature of the information to be remembered. That is, whether its verbal or spatial or musical or autobiographical or semantic. However, memories can also be distinguished in terms of the time interval across which the information needs to be remembered. When we consider this time dimension, memory can again be divided into categories. In particular, a distinction is drawn between immediate, working, and long-term memory.

Immediate memory refers to a system that makes it possible to store small amounts of information over very brief periods of time. Its capacity is very limited – e.g., it cannot deal with more than one or two sentences or about 6-9 digits at a time – and its contents decay rapidly to make way for the next items in the continuous stream of information that enters our awareness. For example, if I read out 7 digits and ask you to repeat them, you’ve engaged immediate memory. In real life, taking down a

telephone number from a friend is a prime example of immediate memory – as your friend speaks the number, you transiently keep the digits online while writing them down and, once that is completed, you promptly forget them as your attention is engaged by the next item in the ongoing stream of consciousness. Indeed, one might speculate that this sort of task has become more important of late because of the increasing use in our society of digit and letter sequences, in the form of telephone numbers, post codes, ATM PINs and internet passwords.

Allied with immediate memory is working memory. This system not only facilitates the temporary maintenance of information in mind, but provides the mental workspace that allows us to simultaneously manipulate that information for some purpose. For example, if I read out a series of 7 digits and ask you to repeat them in reverse order, you have engaged working memory. Similarly, if I ask you to multiply 27 by 3, you need to simultaneously hold and manipulate various bits of information in mind until the answer is provided. Once you’ve done so, however, the mental workspace of working memory will be taken up by some other demand.

Immediate and working memory are crucial systems that make possible our ongoing awareness of the environment and all the events therein. It is closely allied, if not actually synonymous with, the concept of attention. Indeed, many neuropsychologists regard these processes as a part of the attentional system, rather than memory per se. As noted, they are characterised by the brief duration of the memory trace and by limited storage capacity. In contrast, long-term memory is a system or systems that underpin the capacity to store information over minutes-hours-months-years-decades-a lifetime. Storage capacity is virtually unlimited. The declarative and non-declarative memory systems I referred to earlier are forms of long-term memory.

A model proposed by Atkinson and Shifrin in the 1970s and that is probably still useful for our purposes links these different memory systems and suggests how information that reaches us from the environment flows through these various systems to end up as a permanent memory. Critically,

information from the environment is first processed by immediate memory before it enters a more durable long-term store. In short, we need first to attend to information if we are to ever hope that it enters permanent storage.

Why am I at pains to mention this? The answer is that under this model, disruption of this intervening attentional/memory system can render long-term memory systems less efficient. How is this relevant to present discussion? The answer is that in people with epilepsy several factors and co-morbid conditions can impact, sometimes quite significantly, with this intervening system. Chief among these factors are medication and mood.

Anti-convulsant medication

At its simplest, epilepsy represents an abnormal electrical discharge between nerve cells in the brain. The aim of drug treatment is to suppress this excitability. While AEDs are often effective at doing just that, they unfortunately also suppress normal patterns of neuronal excitability more diffusely in the brain. The cognitive manifestation of that is sedation, a state in which normal levels of energy, arousal, attention, vigilance, and mental processing speed give way to drowsiness, slowness of thought, and lapses in focus and concentration. I often use a jogging analogy to make this point – for the person with epilepsy on medication, thinking can often feel like wading through mud rather than sprinting on dry bitumen. Similarly, imagine you've been sleep-deprived for a few days and you're asked to subtract 17 from 35 – the challenge that would pose is what matters are chronically like for some people with epilepsy on medication. In short, the common experience of sedation can disrupt the intervening attention/memory system and result in inefficiencies of memory.

Different AEDs have different effects in this regard. Certain medications are more likely than others to cause sedation. The chance of sedation is also increased with rapid initiation, higher doses, and polytherapy.

Clearly, disruption of this intervening system can further compound memory disturbance in people with temporal lobe epilepsy whose long-term memory system is already compromised.

However, disruption of this intervening system might also cause attentional and memory inefficiencies in people whose epilepsy arises from outside

of the temporal lobe. Indeed, I'd go so far as to suggest that disruption to this intervening system is perhaps the principal source of cognitive difficulties in people with extra-temporal lobe epilepsy. Fortunately, those difficulties tend to be much less disabling.

An important point: This is not to say, however, that people should cease taking AEDs. Ongoing seizures of themselves can be detrimental to both cognition and quality of life and clearly the need to take AEDs to suppress seizures most often trumps any sedating effect they may have. However, I raise this issue because it is important if we are to fully appreciate the factors that can affect cognition in people with epilepsy.

Mood

I will touch briefly on the question of mood disturbance because it too has the potential to disrupt the intervening immediate/working memory system and cause or exacerbate cognitive dysfunction.

The incidence of mood disturbance, i.e., either depression and/or anxiety, is elevated in people with epilepsy. This may be a direct biological consequence of their condition, it may reflect the often significant psychosocial fears and restrictions that accompany the condition, or it may be some combination of the two. Regardless of cause, cognitive disruption frequently accompanies both disorders.

In people who are anxious, excessive and uncontrollable worry and pre-occupation with fears that are irrelevant to the task they need to complete in the 'here-and-now' crowd the mental landscape to the point where focussed attention on other matters is compromised. The tendency to transiently forget one's intention when walking into a room is a common manifestation of this. So too is the realisation that on reaching the bottom of a page one has failed to absorb what you've just read. So too is the phenomenon of losing track of what one wishes to say mid-sentence. Not surprisingly, people often interpret these sorts of attentional lapses as forgetfulness. Not surprisingly too, however, actual long-term memory becomes unreliable in these contexts.

Similarly, low energy levels and associated motivation make it difficult for some people with depression to invest the effort needed for effective attention and concentration. Again, long-

term memory can become unreliable in this context. Indeed, in general neuropsychological practice, and I'm not referring just to epilepsy, anxiety and depression are among the most common causes of a memory complaint.

Language

One final consideration is worth mentioning. As I've already indicated, memory impairment is often present in people with TLE because their epilepsy and memory co-habit the same part of the brain. In addition to memory, another important cognitive domain that is partially housed in the temporal lobe, usually the left, is language. Not surprisingly, therefore, some patients with left TLE experience mild language difficulties. Typically this manifests as a word finding difficulty, that is, difficulty retrieving the name for a particular item. Naturally, this can compound any co-occurring memory deficit.

Closing

H.M. died in December 2008 aged 82. He was a quiet and courteous man with a sense of humour who, referring to his neurosurgeon, once said "What he learned about me helped others, and I'm glad about that."

The early descriptions of H.M.'s memory impairment ushered in the modern era of memory research. They showed that memory could be dissociated from other intellectual and perceptual domains, that memory itself can be subdivided into different domains, and that memory for the episodes of everyday life is critically dependent on the hippocampus and adjacent structures. Subsequent studies showed that people with damage confined to one temporal lobe also have memory deficits, albeit much milder than that of H.M. Typically, people with unilateral damage retain memory for the event, and thus retain a coherent autobiographical record. Frustratingly for them, however, they often experience a tendency to forget the fine details of events they experience and new information they encounter. This is usually most apparent when the damage is on the left and it can be a major contributor to the burden of epilepsy. It can also contribute to the restrictions that epilepsy sometimes imposes on academic achievement and employment. Medication and mood may compound underlying memory impairment through their impact on attention/concentration, focus, and motivation.

SUDEP: global, local and individual perspectives

Dr Rosemary Panelli, Epilepsy Australia

Sudden Unexpected Death in Epilepsy (SUDEP) is not a recent phenomenon but historically, when treatments rarely provided good seizure control, deaths were accepted as a sad outcome of a difficult medical condition. Those who died suddenly were often assumed to have suffocated during a seizure. As modern treatments improved seizure control, epilepsy became less conspicuous in the community and many began to regard it as a minor health issue. Epilepsy information increasingly focused on the positive aspects of modern care, and death slipped from the discussion of risk. In this modern setting, the sudden unexpected death of a young person who is apparently healthy, apart from epilepsy, is rarely expected or accepted by family and friends. It is a totally shocking event aggravated by the fact of not knowing such deaths are possible. More comprehensive investigation of the deaths by post mortem has also revealed that suffocation is rarely the cause of death, adding to the bewilderment of bereaved families and leaving them with many unanswered questions.

Not surprisingly bereaved families felt that action was needed. In 1993 Epilepsy Bereaved was formed in the UK, and SUDEP finally began to attract international attention. Several such organisations now exist internationally and epilepsy specific web sites frequently include SUDEP information.

Two core questions have emerged about SUDEP. Firstly, what causes it and secondly, what should we tell people with epilepsy? There is a reluctance amongst many health workers to talk to patients about SUDEP. If we do not know the cause, it is suggested, how can it help people to know about this risk? Others have argued that despite the fact that SUDEP has no known cause, or guaranteed method of prevention, patients have a right to know that it occurs. This is in line with the contemporary style of Western medicine with its patient-centred approach, and the expectation that patients will be well informed and able to participate in decisions. Risks are routinely disclosed and the community has come to expect this. Families bereaved by SUDEP have felt betrayed in this setting, where they

have not been fully informed.

The identification of possible risk factors for SUDEP through epidemiological research has eased this situation slightly as doctor-patient discussions can now take on the character of a personalised risk assessment. Risk factors can be considered in light of a patient's individual diagnosis and circumstances. As with SIDS, it is hoped that although the cause is not yet known, educating the community about risk factors might prevent some deaths. For example, there are negligible risks associated with certain seizure types and this allows the doctor to provide some reassurance to lower risk patients. Seizure frequency is also a risk factor, which leads well into a discussion with all patients about the importance of striving for the best seizure control possible. Nevertheless, deaths still occur in apparently low risk patients, so while trying to minimise fear it is also important not to create false assurances. Concerns about raising anxiety in patients can be balanced by consideration of the benefits which can accrue from an open discussion. Many patients and parents already harbour fears for themselves or their children which they do not express. Epilepsy educators working in this field argue that careful discussion with a realistic appraisal of an individual's situation often helps to reduce anxiety.

Also important to consider is the ready availability of internet information, much of which is not correct and certainly not tailored to the individual circumstances of the reader. Personal discussion with their own doctor is the best way for people to appraise their risk, and frank, open discussion will facilitate the building of trust in the therapeutic relationship. A recent UK study in a paediatric setting found that 91% of parents studied, expected their doctor to provide SUDEP information, and that it did not have significant immediate or longer term negative impacts on the families. Interestingly one third of the participants had already heard about SUDEP.

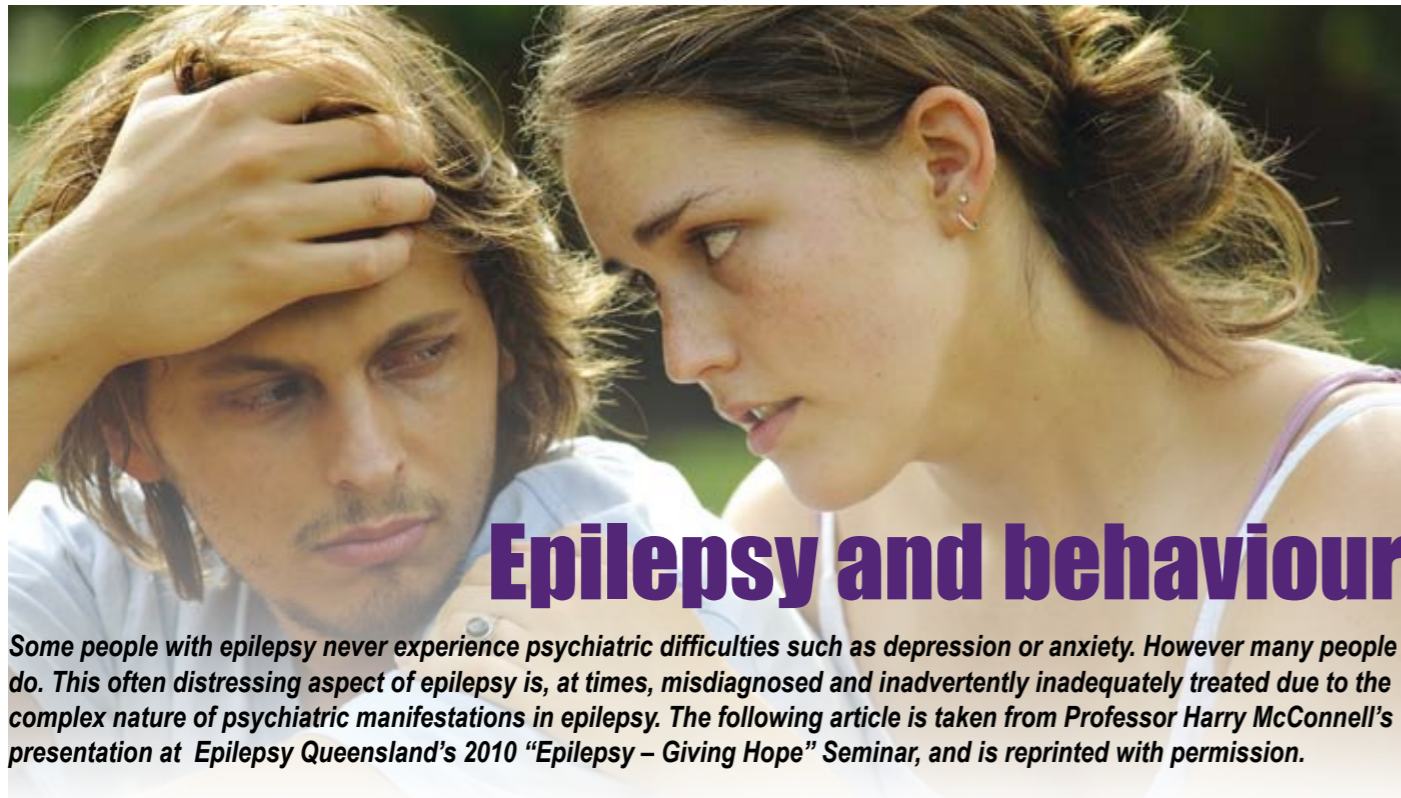
A discussion of SUDEP can sit well in the overall consideration of risk, which is an important aspect of the diagnostic phase. Treatment decisions involve a

comparison of risks and benefits, and although death may not be a common outcome, the catastrophic nature of the event warrants consideration when the diagnosis is explained. Complacency about medication adherence is a common problem in epilepsy. Also, life circumstances can change and a person may decide to reduce or cease treatment without consulting a doctor; unexpected pregnancies can occur for example. If a full disclosure of risk has not been provided early, people with epilepsy may not have sufficient understanding to make safe choices over the passage of time

It is understood that patients vary in personality and coping styles, and therefore in their attitude to information and how they use it to navigate health issues. In settings where risk is introduced to epilepsy patients it would be advantageous to provide additional support workers, to allow for extended discussion where it is desired.

SUDEP continues to be an important topic of discussion and research internationally. Some promising scientific research is starting to emerge and from the clinical perspective SUDEP is a positive influence on the approach to epilepsy management. Guidelines for epilepsy care published in the UK recommend a discussion of SUDEP as part of general epilepsy information and something to be considered when decisions are made regarding antiepileptic drug treatment. In the US an epilepsy taskforce is looking at the priorities for a public health agenda on epilepsy and the blueprint includes a special focus on SUDEP. The epidemiology of risk factors underlines the need to strive for the best possible seizure control in all epilepsy patients and this is a very positive influence on epilepsy care worldwide.

Epilepsy Australia (EA) continues to promote discussion of SUDEP and other epilepsy-related risk. In partnership with bereaved families, people who have epilepsy, Epilepsy Bereaved UK, and colleagues worldwide, EA continues to strive for quality epilepsy care and a reduction in all epilepsy-related deaths. A taskforce has recently been created with epilepsy-related deaths as its focus.



Epilepsy and behaviour

Some people with epilepsy never experience psychiatric difficulties such as depression or anxiety. However many people do. This often distressing aspect of epilepsy is, at times, misdiagnosed and inadvertently inadequately treated due to the complex nature of psychiatric manifestations in epilepsy. The following article is taken from Professor Harry McConnell's presentation at Epilepsy Queensland's 2010 "Epilepsy – Giving Hope" Seminar, and is reprinted with permission.

It has been said that epilepsy is like a snowflake - it affects everyone who has it uniquely and individually. As a consequence each person with epilepsy will experience seizures and their aftermath differently. However, it is now accepted medically, that people with epilepsy are more prone than the general population to develop psychiatric disorders and behavioural disturbances. There are several factors that seem to contribute to this: the disturbed electrical activity in the brain which leads to seizure activity as well as the presence, in some people with epilepsy, of anatomical abnormalities in the limbic system; the social implications of epilepsy such as isolation and stigma are also thought to contribute to psychiatric presentations and, compounding this, some antiepileptic drugs prescribed for seizure control may also have negative effects on behaviour.

Ictal behavioural disturbances

Some seizures cause behavioural disturbances directly. In particular, seizure activity that is focused around the limbic system can present as behavioural or psychiatric manifestations without other, commonly recognised motor symptoms such as jerking or stiffening of muscles. These psychiatric manifestations can include: panic, anxiety, depressive symptoms, auditory or visual hallucinations, feelings of unreality such as *déjà vu* or

psychic symptoms.

For some people with epilepsy, a seizure causes panic symptoms which closely resemble a panic attack. They may experience an overwhelming sense of fear, a feeling that they are going to die, a rapid heartbeat and sweating. Others may experience sudden and acute depression which looks like primary depression disorder. Others will experience psychiatric symptoms such as delusions and hallucinations. This can closely resemble a schizophrenia-like state.

These behaviours or psychiatric disturbances caused by seizure activity are called 'ictal' behaviour disturbances. This means that the behaviours are caused by the seizure activity in a specific part of the brain and occur only while the seizure lasts. Determining whether the behavioural disturbance is due to seizure activity or other causes can be very difficult. Ideally, diagnosis of ictal psychiatric manifestations should be done by an experienced epileptologist who is familiar with a vast array of ictal symptomatology.

It is essential to accurately diagnose whether behavioural disturbances are directly related to seizures, and to differentiate them from psychiatric presentations from other causes, as the treatment of each differs greatly. Generally, psychiatric disturbances such as acute depression, anxiety or psychosis are treated with psychotropic drugs. However, when treating ictal

manifestations these drugs may exacerbate seizure activity in people with epilepsy and lead to further ictal behavioural disturbances.

Post-ictal behaviour disturbances

Post-ictal ("after seizure") behaviour disturbances are behaviours and psychiatric presentations that occur after a seizure has stopped. They are not caused by the seizure directly, but in fact, by the stopping of the seizure.

Fortunately, all seizures must eventually stop. The brain regulates this by releasing inhibitory neurotransmitters (chemicals) to the part of the brain that is experiencing seizure activity. However, the neurotransmitters are not selective and can affect not only the part of the brain that is experiencing seizures, but also the normal tissue around the seizure focus as well. As a result, after the seizure has ended, parts of the brain may continue to be affected by the neurotransmitters. For example, if someone has a seizure near the motor cortex of the brain, they may develop paralysis of the leg on the opposite side of the body to the seizure focus, after the seizure has ended. This is called Todd's Paralysis. This paralysis will resolve spontaneously in a matter of hours to days. Occasionally it can last for weeks.

Similarly, if the seizure is in the limbic system, the effect of these neurotransmitters after a seizure may be more unpredictable and may present

as if it were a primary psychiatric disturbance. The person may appear to have suddenly developed schizophrenia or severe and acute anxiety or depression. To further complicate this, the person who has had a seizure may have a 'lucid' period of 24-48 hours after the seizure where they appear to be completely recovered. During this lucid period they may completely return to their normal state and show no psychiatric disturbances.

The onset of post-ictal symptoms can appear suddenly and apparently "out of the blue". Following the lucid period, particularly after a flurry of seizures or especially severe seizures, people will sometimes develop a range of psychiatric symptoms which include: depression, psychosis, confusion, aggression or agitation. These symptoms may look exactly like a primary psychiatric disorder. However, similarly to Todd's Paralysis, these symptoms will eventually go away on their own. This may take hours, days or even, rarely, weeks.

As with ictal behavioural disturbances, it is essential that the diagnosis and treatment of post-ictal psychiatric and behavioural manifestations be done by an experienced epileptologist, to ensure that effective and supportive treatment is provided. On occasion, the person who develops severe psychiatric disturbances may need short term hospitalisation to keep them safe. They may also be prescribed psychotropic medication to get them through the post-ictal period. However, ensuring that the medication prescribed does not exacerbate the problem is essential. Some psychotropic medications can lower the person's seizure threshold and lead to an increase in the number of post-ictal difficulties. Some people may be prescribed sympathetic long-term psychotropic drugs if they experience recurrent post-ictal behavioural disturbances, requiring ongoing monitoring of their symptoms and medications.

Dealing with behavioural disturbances is one of the most challenging aspects of living with epilepsy.

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Australian discovery leads to development of new AEDs

Professor Adam McCluskey, the director of the University of Newcastle's Priority Research Centre for Chemical Biology, has recently been awarded \$545,000 over three years from the National Health and Medical Research Council (NHMRC) to develop new types of antiepileptic drugs (AEDs) that will only act during an epileptic seizure and will benefit all people with epilepsy, especially those who do not respond to the current AEDs.

Such a novel approach has taken many years to develop. Working in collaboration with Professor Phil Robinson at the Children's Medical Research Institute at Westmead, the new drugs are predicated on Professor Robinson's discovery of the protein dynamin I, which is present in all humans, but in people with epilepsy allows the prolongation of a seizure.

Professor McCluskey's research aims to formulate an AED that inhibits this protein thereby reducing the severity and duration of epileptic seizures.

Everything that happens in the human body is driven by some form of signal. These signals are generated by proteins that interact with other proteins of small molecules, e.g. hormones, within the body. Normally these signaling processes are well regulated and kept under strict control. Every now and then the control seems to fail – this is evident in cancer where the controls that initiate death of aberrant cells seems to fail, in epilepsy these controls let too many signaling events happen at the one time.

For people who do not have epilepsy, the normal frequency of the protein signaling is 20 times per second, but during an epileptic seizure, this signalling hits 500 times a second.

So how will these new drugs work?

Professor McCluskey explains, "The idea here is a bit like a set of traffic lights – when the traffic flow is slow, say early in the morning the traffic flows slowly but continually through – the traffic lights operate "on demand". However as the volume of traffic increases the traffic lights only let so many vehicles through. Our drugs at a bit like the traffic lights – when the volume of traffic is low, all traffic proceeds smoothly, but as the volume increases, our drugs do not allow all of the traffic through – only enough to keep the system ticking over at a steady state."

"We are world-leaders in dynamin inhibitors and they have become important tools for medical researchers around the world. Through our extensive research we have proof that by targeting dynamin I, we can directly inhibit the effects of the disease and reduce seizure severity and duration," Professor McCluskey said.

Professor McCluskey said current AED development pathways had not changed notably in the past 40 years with the majority of AEDs dampening the release of crucial chemical signals. The current drugs also remain constantly active in the body.

"Unlike the current AEDs, our dynamin I inhibiting drugs, will only be triggered at the onset of a seizure. We believe our targeted approach will significantly enhance the day-to-day lives of those afflicted by epilepsy," he said.

Professor McCluskey said the aim was to have the dynamin I-targeted drugs at clinical trials within the next five years.

How predicting seizures has changed Jason's life



In June last year at Melbourne's St Vincent's Hospital, 26 year old Tasmanian Jason Dent became the first person in the world to receive an innovative seizure advisory device designed to predict a seizure before it happens – a device that offered the potential to change his life. Denise Chapman catches up with Jason to see whether this device has fulfilled its promise.

The concept of predicting seizures has tantalized neurologists since the 1970s, because some, but not all, patients can feel a seizure coming on and prepare accordingly. But a systematic warning system has never come close to becoming a reality, until now.

The Seizure Advisory System™ developed by American company, NeuroVista, is a system that involves permanently implanting electrodes on the surface of the brain that continuously monitor the brain's electrical activity. This data is delivered to a small device implanted in the chest that is programmed to calculate the risk of a seizure which is transmitted to a small paging device worn by the patient using a colour coded system: red light (high risk) white light (moderate risk) and blue light (low risk).

Now at the clinical stage of testing, NeuroVista in collaboration with three leading medical centres in Melbourne – St Vincent's Hospital, The Royal Melbourne Hospital and the Austin Hospital, implanted ten patients with the device. Leading the team at St Vincent's that implanted the first device, Professor Mark Cook said "This will really be revolutionary. Predicting seizures is sort of the holy grail of epilepsy therapy.

"With advance notice of an epileptic seizure, a person could ensure that they are in a safe place before they have a seizure. If this device works as we hope, it will reduce the worry and uncertainty

of not knowing when they might have their next seizure. If their risk rating is low, it can also give them the confidence to take part in daily activities most of us take for granted."

For patients with uncontrolled epilepsy, like Jason Dent the first recipient of this device, a warning system that can seizures would be life-changing.

Living with severe epilepsy for most of his life has meant that Jason has had to forgo many things. He even had to give up playing cricket, a game he loves, after having a seizure while batting. He can't drive, cook or live alone. His seizures occur suddenly and without warning. He loses awareness, becomes confused, is unable to respond and often collapses into a convulsion. Even walking down the street can be hazardous; he was almost hit by a car after staggering onto a busy road during a seizure.

Jason has been to St Vincent's a few times since he was 16 to see if he could have surgery to eliminate his seizures. The last time was in 2010 when he was told that as the seizures were coming from both sides of the brain, surgery was not possible. This was a disappointing outcome for Jason as he had been hoping that surgery would provide some lasting respite from seizures.

So when he was asked whether he would like to participate in the trial for this new device, Jason didn't think twice, he grabbed the chance to

' I enjoy the fact that I am not having seizures every fortnight ... I feel like I have more control over my life'

hopefully have some control over his seizures. And on being the first? Jason just said, "It didn't matter – the seizures couldn't have got any worse."

Prior to the surgery, Jason's mum, Helen, talked about how the family managed over the years. "It's always a fear, you're always worrying. We monitor him very closely so it's always where is he? What's he doing? Is he safe? she said. And her hopes for this device? "Just knowing he's safe I think I'd be able to relax a little bit more. And him having some control over something that's been out of control for nearly all his life and unpredictable for all of his life, would be pretty amazing."

With the utmost faith in Professor Cook and neurosurgeon A/Prof Michael Murphy, Jason underwent the three hour surgery that had the potential to change his life forever.

Jason returned home a week after the surgery and over the following weeks the device collected data building a picture of what a seizure looked like in his brain, identifying those periods associated with pre and post seizure activity. This information was sent regularly to Melbourne.

"After approximately six weeks after the surgery, we travelled back to St Vincent's and the device was programmed. When it was turned on the device immediately showed red, which indicated the possibility of a seizure occurring," recalled Helen

"As Jason and I were staying over night to catch up with family, we decided to dine close to the hotel room, rather than travel too far away. As we sat down to dinner, Jason had a seizure – I believe the first predicted seizure in the world – some 5 hours after the device gave a warning! Some close family members, and myself were amazed at how precise the device was.

"We felt confident returning to Hobart the next day, believing that the device would let us know when Jason was going to have a seizure. There is always a concern when flying, as Jason sometimes requires medical intervention when seizures become clustered. That day - no red light! I just knew Jason's life was about to change!"

Adjusting to the technical aspects of the device has not been a problem for Jason. The implant in his chest requires charging each night (although there is enough charge for approx 3 days) and he is also required to place the personal advisory device (PAD) next to his bed on a charger, to monitor him during the night. There are times when he faces away from the PAD during sleep, covering his chest and blocking the signal. Provided the PAD is carried on Jason, it is monitoring his brain activity for 24 hours.

Well it's now been some ten months since Jason's surgery and the outcome couldn't be brighter.

"As time has gone by the results have been better than expected. In the last two months or more I have been taking a fast-acting medication when the device goes red and it has completely stopped my seizures," said Jason.

Jason then explained how the system has allowed him to become more confident in himself. "I carry the medication with me and do a voice recording on the PAD to indicate I have taken the extra medication. I don't walk to or from work, because that involves crossing a busy four-lane highway, until the PAD changes or until a family member can take me."

Jason is also back playing his beloved cricket. While there has been times when the red warning light has come on, Jason has chosen not to play for safety reasons. The cricket club has worked around this and called on other players to fill his spot. Prior to this he would often have a seizure whilst batting which made Jason feel like he was letting the team down and often the team would have to play the remainder of the game short.

When asked how the warning system has changed his life, Jason replied

"I feel more confident in the things that I do from day to day and I enjoy the fact that I am not having seizures every fortnight. I feel like I have more control over my life, as before the seizures would come with no warning and stop me from doing the things that I love doing, like my cricket and time keeping at the local footy games."

According to Helen, Jason's quality of life has improved markedly. He now has control over the things he loves to do:

playing cricket, volunteering at the local Football Club, and work.

"He now has confidence catching buses and travelling to the local shopping centre and visiting friends," said Helen. "As a parent, I do not worry as much as I know that Jason will call me if his device is red. Previously I would contact Jason on many occasions every day and I now limit that contact, as I am confident that he is doing OK.

"This technology has been truly life-changing."

Jason was the first of ten patients to participate in the clinical study to evaluate the safety and effectiveness of the system. In May a further five patients underwent implantation bringing the total to fifteen taking part in the two year trial of the Seizure Advisory System.™

When asked how the trial was going, Professor Mark Cook replied that the data was encouraging.

"While it is still early days with some patients still in the data collection stage so their device has not been programmed yet, the results we have to date indicate the device appears to be working much better than we had hoped and the future looks positive," he said.

"This technology provides us with a new way of looking and thinking about seizures. For the patients, the warning system allows them time to implement risk management strategies, which they didn't have before. For the first time, they now have some control over previously unpredictable seizures thereby improving their quality of life."

NEUROVISTA: Seizure Advisory System™

Developed over five years by American company, NeuroVista, the Seizure Advisory System™ involves permanently implanting electrodes on the surface of the brain to monitor electrical activity 24 hours a day, seven days a week.

A pacemaker-like device implanted in the chest takes this information and calculates the risk of a seizure, sending a risk rating to a wireless personal advisory device (PAD) the patient carries, much like a pager. The

PAD shows whether the risk of a seizure is high (red light), moderate (white light) or low (blue light). The PAD can also be set to vibrate or make a warning sound to alert the patient when the risk level changes.

Armed with this information the patient can make lifestyle decisions based on the level of susceptibility and adjust their circumstances during the course of the day – make sure they are safe, notify others, or the possibility of taking a fast-acting drug to prevent it.



Celebrating Purple Day 2011

26
March

The simple message of Purple Day – wear purple and raise awareness of epilepsy – captured the imagination of people with epilepsy across the country. The challenge to ‘go purple for epilepsy’ was taken up with great enthusiasm by corporations, sporting bodies, schools, retail outlets and the community in general, all eager to participate in raising awareness of epilepsy.

Our incredible Purple Day Heroes spread the word among colleagues and friends selling Purple Day merchandise, baking ‘purple’ cupcakes and muffins, holding their own events to raise not only awareness of epilepsy but also valuable funds to help us continue our work providing services to people living with epilepsy.

Thousands of students participated in awareness raising events – from one-teacher country schools to city colleges – all learning more about epilepsy and what to do if they saw someone having a

seizure. Epilepsy awareness was created among music fans with gigs in Sydney (see insert below), and in Blacktown where Mark Cashin and the L’il Husseys promoted awareness while performing live for breakfast radio SWR FM 99.9.

The Epilepsy Foundation of Victoria launched Purple Day with event partner Melbourne Storm at the Storm vs Titans clash on March 19. Aired by Fox Sports with over 13,000 fans in attendance, Epilepsy Foundation volunteers eagerly rattled tins and handed out wristbands promoting the Epilepsy Smart Quiz. Storm champion, Adam Blair, joined forces with well-known Collingwood supporter Joffa, to spread the word of Purple Day.

The Seymour Racing Club came on board, naming Race 8 on the program the National Epilepsy Awareness Day - March 26 with the jockeys wearing purple arm bands. This midweek meeting was televised throughout Australia and New Zealand providing invaluable promotion.

In South Australia the servicemen at Edinburgh RAAF Base eagerly filled volunteers’ collection tins, while in Perth a fun day was held at the West Australian Epilepsy Association offices.

Epilepsy Queensland held a free seminar on developing new treatments for epilepsy with keynote speakers Professor Terence O’Brien and EQI Patron Wally Lewis. With support from up and down the coast, Queensland’s Gin Gin Pharmacy won the inaugural Purple Pharmacy competition.

Epilepsy ACT marked Purple Day/ Epilepsy Awareness Month with Senator Gary Humphries launching a new publication *Epilepsy in the workplace: a guide for workers and employers* at the Legislative Assembly of the ACT.

But it was the participation of people with epilepsy themselves, their families and friends that really made Purple Day 2011 such a success. You are our heroes!

2012 is shaping up to be even bigger and better - mark the date now!



Sydney bands support epilepsy awareness by Felicia Eccles

On Thursday 14th April, a crowd of 50 people gathered at The Annandale Hotel to support a fundraising gig for epilepsy awareness!

The music started with a magical set from Microwave Jenny, followed by The Rescue Ships – an amazing duo consisting of the talented artists, Elana Stone and Brian Campeau.

The headliners, The Paper Scissors arrived onstage and apologised in advance for their set being a lot louder than the other two. However they soon had people up at the front, dancing and singing along. The energy was fantastic and The Paper Scissors were, as always, amazing, thoroughly entertaining and literally had the crowd cheering for more!

The Annandale is a fantastic venue and a stalwart of the Sydney music scene, so I was honoured that they jumped on board to help me with my fundraising. It is very heart-warming to have them supporting me when they are possibly facing the end of an era with the hotel going up for auction very soon.

I was also truly humbled by the bands’ support. The event definitely created awareness and expressed the importance of supporting and funding the efforts of Epilepsy Australia.

The experience has inspired me to do this again, so keep your eyes and ears open – there may just be a Purple Day fundraiser gig in 2012! Special thanks goes to Kristie Jane Hogan for making it all happen, everyone at The Annandale, The Paper Scissors, The Rescue Ships, Microwave Jenny and to the photographers, Katie Armstrong and David McSorley.



The Rescue Ships photo: David McSorley



Microwave Jenny photo: David McSorley



The Paper Scissors photo: Katie Armstrong



2nd Australian & New Zealand Dravet Syndrome Family Conference

Jean Ewing, Epilepsy Foundation of Victoria

On March 19th 2011, Epilepsy Australia, through the Epilepsy Foundation of Victoria, supported the Second Australian & New Zealand Dravet Syndrome Family Conference, following the inaugural conference two and a half years ago. The conference was the initiative of a team of dedicated parents, led by Sam Jackson and Tom Philbin, together with the support of Jean Ewing from the Epilepsy Foundation of Victoria, and Professor Ingrid Scheffer of the Florey Neurosciences Institute and the University of Melbourne. Around 150 people attended the conference including families from New South Wales, Queensland, Victoria, South Australia, and Tasmania. The conference was held at The Royal Children's Hospital and childcare was provided by Year 12 volunteers from Sacré Cœur, a girl's school in Melbourne, supported by two trained child care workers. The conference was recorded by media students from Deakin University.

Dravet Syndrome, also known as Severe Myoclonic Epilepsy of Infancy (SMEI), was first described by Charlotte Dravet in the early 80's. In this disorder, previously normal babies develop

seizures at around six months of age, triggered by fever. They present with prolonged seizures typically with jerking down one side (hemi-clonic), or all over (generalised tonic clonic seizures) with fever, resulting in attendance at emergency departments. The baby then goes on to have frequent convulsive seizures, often status epilepticus, between six months and one year of age. Other seizure types develop over the following years, including different types of staring spells (both absence and complex partial seizures may occur) and myoclonic jerks. The seizures are hard to control with antiepileptic medication, and over the early years of childhood, intellectual slowing and sometimes regression occur. These children have poor intellectual outcome, and the seizures often remain uncontrolled into adult life. As toddlers and young children many experience very difficult and challenging behaviour. Families are faced with a myriad of problems: uncontrolled epilepsy, declining intellectual functioning, behaviour disorders, eating disorders, and orthopaedic concerns.

The aim of the conference was

to enable families to hear the latest information about their children's condition. Speakers from a wide range of disciplines presented up-to-date information and answered questions from the audience. Speakers included:

- ♦ **Professor Ingrid Scheffer** from the Austin and Royal Children's Hospitals, Melbourne, Victoria, who outlined the latest research on Dravet Syndrome. In the last ten years, Professor Scheffer lead a research program into this condition and has shown that approximately 70 per cent of children with Dravet Syndrome have a mutation of a specific gene. The gene is called SCN1A and encodes a subunit of the sodium channel which is a gateway into the cell. 90 per cent of the SCN1A mutations are new in the child, which means that neither parent carries the gene. This is important for many reasons, not least of which is that Professor Scheffer's group's research has debunked the mythology around so-called "vaccine encephalopathy" by showing that the majority of children whose seizures and developmental concerns were triggered by the vaccination actually had the genetic

mutation and were destined to have this disorder.

Professor Scheffer outlined for parents the future they might expect for their child's development and seizures.

- ♦ **Judy Nation**, Senior Dietician from the Royal Children's Hospital, Melbourne, Victoria, discussed the eating difficulties many of the children experience, particularly their poor appetites due both to their general fatigue because of their many seizures and side effects of their medication. She discussed strategies to help them eat and also spoke about the Ketogenic Diet as a means of enhancing seizure control and maximising the developmental potential of the children.

- ♦ **Dr Sian Hughes**, who spoke next, is a consultant Paediatrician specialising in working with children with behavioural and learning concerns and who has a particular interest in autism spectrum disorders. Dr Hughes stressed the importance of developing regular sleep habits both to enable the children to derive maximum benefit from their schooling, and to allow their parents to minimize their own sleep deprivation and therefore cope more adequately

with the demands of running a family with other children and a child with significant extra needs.

- ♦ **Helen Johnston**, Principal Mt Evelyn Special Development School and Helen Hatherly, Principal of Ashwood Special School and President of The Specialist Schools Principals Association, spoke about the range of schooling options and support in Victoria. They gave parents strategies about how to determine the best educational path for their child.

- ♦ **Several parents** of children with Dravet Syndrome, and a young adult with Dravet Syndrome, gave varying perspectives on parenting a child with this difficult condition and the issues they have confronted. As always, these personal stories were both very moving and extremely supportive for the families attending the conference.

- ♦ **Jean Ewing**, from the Epilepsy Foundation of Victoria, gave a brief overview of the range of services and supports available for parents and families.

The evaluation sheets completed by many parents at the end of the conference indicate that the participants

derived much value from the day. Families found the information to be relevant, presented in an understandable way, "common sense without medical jargon." There were many suggestions for changes to the format, a deep appreciation of the parents who shared their experiences, and gratitude for the opportunity provided. One of the outcomes of the First Conference held in 2008, was the establishment of the Dravet family network, which enables families to have contact with each other, sharing experiences and insights. This network will be further expanded after the recent conference.

The important "take home" messages were:

1. Families are dealing with a difficult medical condition which is the result of a new genetic mutation, and not the result of something they have done.
2. The child's intellectual disability and behavioural difficulties are part of the syndrome.
3. There are services available to support families in managing their child's condition, and parents need to seek out these services for their child. ■



Epilepsy and its link with bladder and bowel function

For people with epilepsy, experiencing problems with bladder or bowel control can be a common occurrence. Incontinence means any amount of unwanted leakage from the bladder or bowel and it can be either ictal (i.e. pertaining to a sudden acute onset of a convulsion or seizure) and/or the leakages happen perhaps occasionally or throughout the day. There is about 4-5 times the likelihood of incontinence associated with epilepsy compared with the general population.

Incontinence – like epilepsy – is not only “physical”, but is also linked with neurological and psychiatric conditions. The nearly 5 million Australians coping with poor bladder or bowel control can find it annoying, embarrassing, frustrating, distressing or depressing, depending on the severity. At whatever level, it can affect our quality of life – socially, emotionally and financially.

Just as there are a number of types of epilepsy, each person’s incontinence manifests in a unique way. It will have either slight or significant impacts on lifestyle depending on its severity and the person’s age, health profile, personality and living circumstances. Incontinence is individual to each person and has many “faces”. Its management and treatment will need to be tailored and perhaps involve more than one healthcare area – specialist doctor, continence nurse advisor, continence physiotherapist, aged care specialist, for example.

Incontinence, like epilepsy, touches every age-group and its management in young people compared to older Australians will be different. Incontinence in aged care, for example, will involve its associations with health problems that tend to become more common with increasing age. Prostate-related urinary problems and incontinence post-prostatectomy (surgery) are fairly common in middle-aged men and older. For older patients, the effects of a seizure’s aftermath can be prolonged, with brain function issues such as incontinence, confusion,

wandering or paralysis persisting for several days. It is also suspected that a long-term history of epilepsy may cause neurological damage which may affect continence apart from the sudden leakage that occurs during a seizure, in a similar way that neural pathways are damaged by a stroke, for example.

Incontinence can be stress, urge, functional, overflow or mixed, so it’s important to understand exactly what factors are involved: incontinence is complex, often with several factors interacting. The higher prevalence of incontinence in people with epilepsy is probably related to ictal incontinence as well as incontinence related to a neurological comorbidity, such as people recovering from a stroke or who have Alzheimer’s, the most common form of dementia.

Just as epilepsy diaries record seizures and the events around these in order to throw light on the effects of medications, so a bladder diary or a bowel chart can reveal the volume and incidence of bladder and bowel leakages, patterns and perhaps relationship to certain foods or fluids. These diaries are useful tools, both for the awareness of the person with the condition and for their clinicians developing treatment/management strategies. They also provide a baseline to show changes over time, which can sometimes be quite subtle.

There are many treatments for incontinence, from simple tactics to try at home right through to surgery. Continence physiotherapy and pelvic floor muscle exercises could be appropriate for you if stress urinary incontinence and pelvic floor muscle weakness are involved. Medications can modify bladder function, or perhaps a regime of laxatives or a dietary fibre supplement will help get the bowel regular. Normalising bowel function is a skill best left to a doctor or continence nurse so get professional advice about this aspect of continence management.



Anne Ramus
Continence Foundation of Australia
and National Continence Helpline

What is the “overlap” feature called comorbidity (the association between various other health conditions)?

Epilepsy is a comorbidity of many other chronic (i.e. ongoing) health conditions and this also applies to incontinence. For a variety of physical and neurological reasons, incontinence “flows beneath” many other health conditions like diabetes, heart or prostate problems, dementia, stroke, or spinal injury, neurological conditions such as Multiple Sclerosis or Parkinson’s, and chronic coughing such as in asthma or smoker’s cough. While certainly not “health problems”, pregnancy/childbirth and menopause later in a woman’s life are the most common reasons for incontinence; hence, its prevalence among women is much higher than for men (whose incontinence issues are commonly prostate-related). The incidence in women who have ever had a baby is high: about 1 in 3 will have urinary incontinence at some point. In older age groups, the prevalence rates in men and women become increasingly similar.

Frequent nocturia, where a person has to get up several times during the night to visit the toilet, is a continence-related condition common in older people and has a range of causes. Frequent toilet visits can result in “training” the bladder to have a smaller capacity. Nocturia

also contributes to sleep deprivation with physical and mental tiredness the following day. Sleep disturbances are associated with antiepileptic drugs (AEDs). AEDs can cause people to sleep very deeply and bedwetting can result.

The prevalence of epilepsy in people with an intellectual disability (ID) is higher than in the rest of the population, with one study quoting 26% prevalence of epilepsy with ID. ID has implications for incontinence, both functional and physical/neurological.

Many family caregivers look after the interests of people with a wide range of health conditions which commonly carry incontinence as a comorbidity, including epilepsy. The continence nursing burden of both epilepsy and incontinence on an at-home carer is understandably considerable – especially for older carers who are commonly in need of care themselves. One of the three top reasons for admission to residential care, along with mobility and dementia, is incontinence, with faecal incontinence often “the last straw”.

Why is it important for continence management to take account of the epilepsy?

Understanding exactly how epilepsy manifests for the individual person is important because this will have implications for how the incontinence is managed. Both incontinence and epilepsy are complex and, while their interactivity can certainly complicate matters, the link of epilepsy with other health conditions (including incontinence) offers potential for a range of treatment and management possibilities – provided all conditions involved are well understood and addressed.

This highlights the importance of getting good professional advice for a bladder or bowel control problem. A thorough continence assessment is recommended as a first step and the National Continence Helpline can provide contact details for a local continence service or your doctor may organise this. This detailed picture forms the basis of an effective management and treatment plan, customised to suit the individual person. The issues highlighted by this

continence assessment could include the effect of epilepsy and its drugs, whether the person is overweight, is taking medicines for other health conditions, their living arrangements (if in residential care or living alone, for example) and whether they have any other psychological or physical challenges. Sometimes, incontinence can also be a pointer to another unrecognised health problem.

It is simply wrong for anyone, either patient or doctor, to put pro-active continence management into “the Too-Hard Basket”. Incontinence deserves to be looked at in its own right, and evaluated, treated and managed in the light of all interacting factors.

Drugs: a downside to the upside?

Drugs are an important part of health management, but no drug is without its side-effects. Drugs are a common issue with incontinence because there are so many prescription drugs and over-the-counter medicines taken for other health conditions that can cause or contribute to poor bladder or bowel control.

For epilepsy, gastro-intestinal (digestion-related) complaints are common in patients taking AEDs, especially the older types of drugs. Anything affecting digestion may have continence implications. Some antiepileptic drugs, antispasmodics and anticholinergic drugs for bladder instability (and combinations of these) are risks for constipation. Careful, individual bowel management using bulking agents or stimulants is important here. Laxatives – even though readily available as over-the-counter medicines – are generally not recommended for long-term use (as they may cause a “lazy bowel”) unless a selected laxative or combination of laxatives is part of a regime devised by a clinician. Again, professional advice and ongoing monitoring are essential.

The role of exercise and diet in continence management

Daily exercise is important for every aspect of our health and wellbeing and incontinence is no exception. Regular exercise helps avoid constipation, a first line item for a clinician addressing a continence problem. Constipation and straining in the toilet can weaken

the pelvic floor muscles necessary for good bladder and bowel control and an over-full bowel can press on the bladder, affecting its capacity and stability.

Generally, a high-fibre diet (unless otherwise advised by a clinician) will be one dominated by cereals, fruit and vegetables, plus a good daily fluid intake. This is “the bottom line” in promoting good bladder and bowel function. Avoiding some common drinks which are known “bladder culprits” (notably alcohol, caffeine-containing and perhaps fizzy soft drinks) can help keep the bladder under better control.

A too-common tactic to avoid urine leakage is to cut back on fluid intake: rather than keeping one “dry”, the opposite can result: the concentrated urine irritates the bladder lining making it more unstable (toilet frequency or urgency). Low fluids can also contribute to constipation. More drinks (water is best) are needed in hot weather and with higher exercise levels too. The broad recommendation of 1.5 litres of fluid daily can vary from person to person, so it’s best to check with your doctor if in doubt.

Fatigue is a major side-effect of AEDs and seizures themselves can fatigue a patient so the exercise picture is complicated by tiredness, anxiety or depression. Heart disease, high blood pressure and being overweight make the common association of epilepsy and incontinence even more complex.

Social continence

For many people with epilepsy who have to cope with a sudden loss of bladder or bowel control, wearing a continence product during particular “at risk” times (or continually if needed) can preserve “social continence”. However, it’s important to also get good continence management advice – and not merely “pad up and bat on”! For reasons of comfort, security and cost, expert advice ensures the most suitable continence products and where to get these. Most suppliers can mail supplies in discreet packaging.

Eligibility for some financial assistance via State schemes or the Continence Aids Payment Scheme (CAPS) is worth exploring. Continence products can put a big hole in the household budget, so it’s good to get advice about possible funding support. The National Continence

Helpline's advisors can assist with information about eligibility for CAPS and the application process.

Attitudinal issues around incontinence

Incontinence can be associated with mental states such as depression and anxiety. Being anxious about leaking and cutting back on social activities or work (both paid and voluntary), avoiding health sport and exercise, and possible damage to close relationships are significant quality of life issues for many Australians with incontinence.

Our society's "baggage" around incontinence is certainly considerable. It may in fact be the last health issue to move into the healthcare spotlight. There are many myths around incontinence that can be "busted": it's wrongly associated simply with "getting old" or "just because I've had a baby", or that it's "dirty", "it's my own fault" or shows "a lack of control". It might be feared as being "childlike", perhaps relating to the negative bedwetting experiences of childhood in an age less understanding of the real underlying factors.

Because our society is set up with these attitudes, incontinence can be hidden from doctors as shameful or perhaps not worthy of attention, rather than being viewed as another health condition deserving of expert help. We don't talk about urine, yet it's okay to mention blood, sweat and tears – those other bodily fluids! Bowel (faecal) incontinence – harder to hide and clean up afterwards than urine loss - is understandably even more of a taboo topic.

Up close and personal

Urinary and faecal continence problems, perhaps in similar ways to epilepsy, may inhibit people with their sexual expression. They may be fearful of having "leakage accidents" during sexual activity. Pain, sensory disturbance, tremor and numbness can affect the bladder and bowel. Anxiety and depression, stress, lowered self-esteem, fatigue, effects of medicines and cognitive impairment may also be involved. Sexuality is a significant quality of life issue and if there are problems, the recommendation is to seek the professional advice of your doctor

and/or a sexual counsellor.

Social isolation can become an issue. Increasing fears of wetting in public or the prospect of coping with a bowel episode can make it easier to simply stay home. Planning one's day around the nearest toilet and being anxious about leaking can ruin what should be an enjoyable social event. Choices to stay at home can affect relationships with friends and family, with problems of self-esteem, loneliness, depression or falling confidence. Healthy exercise levels can suffer too if there is leaking or flooding during exercise at the gym or while out walking. Smoking or alcohol abuse can become secondary problems and, along with their effects on general health and wellbeing, can further impact bladder and bowel function.

Professional help with continence management

Often the fears and shame around incontinence stand in the way of people seeking expert help. It's never too late to do this – and it's never too early either: a so-called "small" incontinence problem won't get better on its own and will probably worsen over time if unaddressed. It's wise to seek advice when a so-called weak bladder or misbehaving bowel first become apparent.

You may feel embarrassed or uncomfortable talking about incontinence, especially for the first time. It can be helpful to read the resources from the National Continence Helpline or speak to one of the Helpline's continence nurse advisors: the service is free and confidential and you can ring from the comfort and privacy of home.

In a nutshell

It remains to be seen whether the patterns of comorbidity around epilepsy are specific to it, or simply reflect the associations which occur in chronic illnesses generally. However, the incontinence message is clear for doctors and patients: bladder and bowel function does not stand alone, but will relate to other health issues, including epilepsy – perhaps even another health issue as yet undiagnosed.

The incontinence/epilepsy picture is a complex one involving the types of epilepsy and incontinence, their

relationships with other co-existing health problems, within people's different living environments, with individual perceptions, personalities, attitudes and capacities.

A thorough understanding of all the interacting issues via a continence assessment is the best starting point. Incontinence can almost always be better managed, treated and sometimes cured. Treatment options range from the conservative, "at-home" approaches, perhaps continence physiotherapy or bladder training, through to surgery.

While commonly associated with epilepsy, incontinence is deserving of clinical attention in its own right. This will improve both its management and treatment, for reasons of physical, mental and emotional considerations in the maximising of a person's quality of life.

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For further help ...

National Continence Helpline 1800 33 00 66 – continence nurses providing information on the many aspects of bladder and bowel function, including leakage, constipation, diarrhoea, toilet frequency and urgency. Product information includes advice about choice of continence products, suppliers, and eligibility and the application process for financial assistance schemes. Contact details for a local continence clinic are available along with free resources on a range of continence-related topics, including bladder and bowel diary sheets.

On the 'net ...

Continence Foundation of Australia
www.continence.org.au

Australian Government
www.bladderbowel.gov.au

Depression and anxiety information www.beyondblue.org.au

APA scholarship reward for hard work

Following the completion of his Masters of Philosophy (MPHIL) degree in April, 2009 Martin Raffaele began doctoral studies looking at men with epilepsy and their challenges with Subjective Well-Being (SWB) following elective neurosurgery for Adult Onset Epileptic Seizures (AOES) activity; the challenges a man faces when returning to social environments, including the home, medical, and general societies. Martin's individual approach to this research is to focus on a small group of men that could be interviewed individually and record the circumstances that they personally experienced, rather than base his findings on general information gathered from questionnaires.

As Martin explains, "A challenge that often arises for a man following neurosurgery to control seizure activity, is dealing with the attitudes of others in relation to what goals they now feel he is capable of achieving.

"My decision to study at university following the second left temporal lobectomy in 2000, and continue to do so up until this point, with my Ph.D being the 4th degree, has been strongly questioned by many people in these societies. When people believe someone is only capable of achieving limited goals as a result of neurosurgery, this can often affect subjective well-being, or

how an individual judges himself and his place within all societies."

One of the difficulties Martin faced academically when studying the MPHIL was the need to read large amounts of published articles relevant to his research at that time. A software programme titled Kurzweil 3000 was provided by the university's Disability Services department, which greatly assisted him with this process. Although the seizure activity he continued to experience following the operations had dramatically reduced as a result of the procedure in 2000, the fear that is often experienced by others as a result of not understanding epilepsy saw tension arise, as was being provided with a personal office on campus, which was necessary so that he could use the Kurzweil 3000 and Dragon Naturally Speaking without surrounding sounds interrupting the process.

Martin successfully completed the degree in April 2009, with the 40,000 word thesis. It was following this degree that he began to collect and read articles and books that would be relevant to his PhD research.

In August 2010, following the commencement of his PhD, Martin was awarded an Australian Postgraduate Award (APA). The Australian Government presents the APA scholarship to students with exceptional



research potential who undertakes a higher degree by research.

Receiving this award has validated the years of persistence Martin has applied to his studies. To finish his Ph.D Martin will need to interview men who have undergone brain surgery to reduce adult onset epileptic seizures.

Martin believes that the results of his research will be of benefit for all societies, "We cannot live alone; we are learning to live together with happiness.

"Knowing that my experience can support other people is the best way for me to maintain a high energy level to achieve the understanding of epilepsy from the perspective of those with the condition."

For those interested in Martin's research he can be reached at martin.raffaele@gmail.com

2010 excellence in journalism awards announced

In announcing the winners for 2010, Mike Glynn, award judge and President of IBE, commented, "This year's Excellence in Epilepsy Journalism Award saw an increased number of entries, with the overall standard being particularly high. A total of 43 entries from 17 countries were submitted, ranging from messages of hope to moving personal accounts, which reflects that the consistency of message on epilepsy is united across the globe. We congratulate and thank all journalists who submitted entries for their dedication to responsible and educational reporting on epilepsy."

Makiko Tatebayashi was the winner of the Print category for her article Let's Know Epilepsy, which featured as a seven-part series in the Japanese newspaper Yomiuri Shimbun.

Jessica Solodar was the winner of the Online category for her article Seizures triggered by video games: Underestimated and undiagnosed which was posted on the website epilepsy.com.

The winner of the Broadcast category was Niamh Maher, series producer for "This Is Me", for her documentary "Not Out", which was broadcast on Raidió Teilíffis Éireann 1.

The 2011 award is now open to journalists around the globe, who can either submit their own work or be nominated by a third party.

There are three categories for entries – print, online and broadcast, with one winner to be selected from each group.

Entries can be about any aspect of epilepsy and must have been published or broadcast between 30th October 2010 and 30th November 2011.



To download an entry form, go to <http://www.ibe-epilepsy.org/news/2011-excellence-in-epilepsy-journalism-award-now-open>

Zonegran (zonisamide) now available in Australia

Zonisamide (Zonegran®) is the latest antiepileptic drug to be added to the Pharmaceutical Benefits Scheme (PBS).

While it is a new drug in Australia, zonisamide has been used in Japan and Korea to treat epilepsy since 1990, in the United States since 2000, and in UK and Europe since 2005.

Zonisamide capsules are indicated

as adjunctive therapy in the treatment of adults with partial seizures with or without secondary generalisation.

Listed on the PBS from 1 April 2011 as an authority streamlined benefit, zonisamide provides specialists with an additional option with which to treat those who have not responded to other medicines.

One-in-three forget to take their medicine: NPS survey

New findings from a survey conducted by the National Prescribing Service have shed some light on exactly how Australians are using – and misusing – medicines.

Of 1500 Aussies surveyed 29% said they sometimes forget to take their medicine and while most never intentionally miss a dose (67%), take less than instructed (71%) or more than instructed (87%), NPS clinical adviser, Dr Danielle Stowasser says taking a casual approach is never a good idea.

“Every medicine you take should come with clear instructions, including things such as the maximum dose and the frequency which you can take it. Ignoring these instructions can put your health at risk. Taking more can result in an overdose, while taking less might stop the medicine from doing its job. That’s why it’s important people ensure they always follow the instructions carefully and if they are unsure, seek further information from their health professional.”

While most respondents said they would seek information about their medicines from health professionals, when asked if they did ask questions of their doctor or pharmacist the last time they received or purchased a medicine, most said no (60%).

“Asking the right questions about your medicines is crucial to being medicinewise and will give you the information you need to make better choices about your health,” Dr Stowasser said.

Equally important is discussing what

other medicines you’re taking with your health professional before starting a new medicine. The survey found 48% of respondents did not tell their doctor or pharmacist about other medicines they were taking the last time they received or purchased a medicine.

“All medicines, including prescription, over-the-counter and alternative and herbal, have the potential to interact with other medicines so it’s important you let your doctor or pharmacist know about all the medicines you are taking before starting any new medicine,” Dr Stowasser said.

“We want all Australians to be actively involved in their medicines decisions, so they get the most out of them and reduce their risk of adverse events. The quality of medicine information from sources other than your health professional can be difficult to judge, and making decisions based on incorrect or misleading information can be dangerous,” Dr Stowasser said.

To help people learn more about finding credible sources of information and what to consider before starting a new medicine, NPS has developed a series of free online learning modules called Medicinewise Choices.

The NPS Medicines Line **1300 633 424** is a free telephone service providing consumers with information on prescription, over-the-counter and complementary/herbal medicines.

 For more information about the Medicinewise Choices visit www.nps.org.au/medicinewisechoices



Australian Pregnancy Register

This voluntary, nationwide study that is enrolling women who are currently pregnant or who have given birth recently (infants up to 6-9 months of age) in the following categories:

- Women with epilepsy taking antiepileptic medication (AEDs).
- Women with epilepsy not taking AEDs.
- Women taking AEDs for allied conditions.

To participate in this study call **1800 069 722**


 For more information about the Australian Pregnancy Register visit www.apr.org.au

AUSTRALIAN LONGITUDINAL EPILEPSY STUDY

Australia’s first longitudinal study of epilepsy looking at needs, perceptions and experiences of people living with epilepsy is underway.

If you are a person living with epilepsy or the carer of a person living with epilepsy and you are interested in taking part in the survey, all you need to do is call the Epilepsy Foundation of Victoria on 03 9805 9111 or email epilepsy@epilepsy.asn.au and a registration form will be sent to you.

Your participation will help shape the future for all Australians living with epilepsy.

 For more information about this study visit www.epilepsyaustralia.net/Current_Issues/Research

The National Relay Service (NRS)

a service for people who are deaf, hard of hearing or who have speech impairment

Dr Christine Walker

Did you know that about one in six Australians is either deaf or has a hearing impairment? There are others who have difficulty speaking. Some hearing impairment affects all of us as we grow older. I didn’t know this until recently and it made me think that for older people with epilepsy, in particular, hearing impairments are just another problem they face. For older people who have had a stroke speech might also be difficult.

Some people with epilepsy already feel socially isolated so that not being able to hear or perhaps speak well makes them just that more isolated.

The National Relay Service set up by the Australian Government in the 1990s is a service that people with epilepsy in this situation can benefit from.

For the price of a local call anywhere in Australia a person can make a call through a ‘relay officer’. If you can’t hear but your speech is clear then you speak and the relay officer types BACK the other person’s exact words to you. If you can’t hear and can’t speak clearly then you type your message and the relay officer types the reply from the other person back to you. If you can’t speak but you can hear then you type and the relay officer speaks your words and the person on the other end speaks directly to you. Some people might have difficulty understanding your speech but if you can hear then the relay officer can re-speak your words over an ordinary telephone. These relay officers are specially trained to understand impaired speech.

The NRS can provide free training in a person’s home as well as taking down your details and keeping them on file so that they know immediately you use



The **National Relay Service** can help people with hearing or speech impairments have good phone conversations with less misunderstanding and repetition. They can get things done such as make appointments and business calls, and keep in touch with friends and family.

the service what your preferences are regarding text and speech.

People who type use a special phone called a text phone (TTY) which has a screen and a keyboard or an internet relay on a computer. They may be available through a phone company as part of their disability access scheme and be a similar cost to an ordinary home phone.

If people prefer internet relay the connection is through an internet connection which can be on the home computer, a laptop or internet connected mobile phones. However there is a problem here because you can’t receive calls or in some cases make emergency calls.

The other good thing to know is, if you know someone who is deaf, has a hearing impairment or speech difficulty you can call them through the NRS. You don’t have to wait for them to call you. If they use TTY you just have to have an ordinary phone.

Of course, having contact with the outside world is very important in an


emergency. The 106 TTY Emergency Service was the world’s first national text emergency relay service giving access to police, fire and ambulance services.

The service is manned around the clock. Call **133 677** for TTY/voice calls and for Speak & Listen calls, the number to call is **1300 555 727**.

NRS is committed to protecting the privacy of the content of all calls and the identity of callers.

The NRS website has lots of easy to read information available. There are stories and videos that demonstrate the ease of the service.

I would suggest that people who might be concerned with their hearing loss visit the website.

 For more information about the National Relay Service visit www.relayservice.com.au



A Great Place for a Seizure

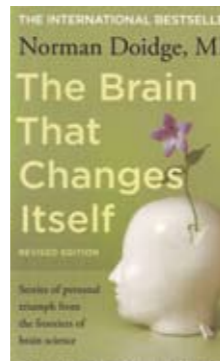
Terry Tracy
CreateSpace
ISBN: 978-1453834701

“A Great Place For A Seizure,” a debut novel by author Terry Tracy, gives readers a glimpse of life with epilepsy. Mischa Dunn’s family leaves Chile in the wake of the 1973 coup d’etat that installs a military dictatorship. She settles comfortably in her newly adopted country, the United States, until one day an unexplained seizure in a library transforms her forever. The novel follows Mischa from adolescence to adulthood as she struggles to deny, defy and accept her epilepsy.

Through humor and insight, Tracy draws the reader into Mischa’s tale that travels across three continents over thirty years. Mischa’s family and friends accompany her on this journey with hopes for the better and painful confusion over how to help. An unusual heroine, Mischa is not a glorified survivor, but an individual with obvious flaws and some virtue. “A Great Place for a Seizure” is not the story of a disability, but of a life led with a disability.

Terry Tracy’s careers as a human rights activist, journalist and diplomat have taken her around the world. In 2007 she was one of the founders of a disability advocacy group for employees in the U.S. State Department. Tracy has lived with epilepsy for more than 25 years. She resides in London with her family.

Available through Amazon.com, the paperback retails for \$12.95, with the Kindle edition available for \$2.99.



The Brain That Changes Itself

Norman Doidge, MD
Scribe Publications, Vic.
ISBN: 978-1921372742

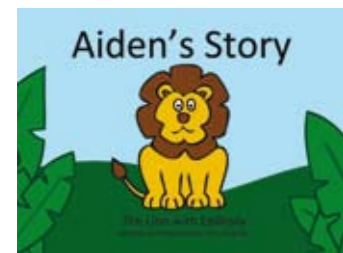
An astonishing new scientific discovery neuroplasticity is overthrowing the centuries-old notion that the adult human brain is fixed and unchanging. It is, instead, able to change its own structure and function, even into old age.

Psychiatrist and researcher Norman Doidge, MD, travelled around the United States to meet the brilliant scientists championing neuroplasticity, and the people whose lives they’ve transformed – people whose mental limitations or brain damage were previously seen as unalterable, and whose conditions had long been dismissed as hopeless.

We see a woman born with half a brain that rewired itself to work as a whole; a woman labelled retarded who cured here deficits with brain exercises and now cures those of others; blind people who learn to see; learning disorders cured; IQs raised; ageing brains rejuvenated; stroke patients recovering their faculties; children with cerebral palsy learning to move more gracefully; entrenched depression and anxiety disappearing; and lifelong character traits changes.

Doidge takes us onto terrain that might seem fantastic. We learn that our thoughts can switch our genes on and off, altering our brain anatomy. We learn how people of average intelligence can, with brain exercises, improve their cognition and perception, develop muscle strength, or learn to play a musical instrument – simply by imagining doing so.

Using personal stories, Doidge’s inspiring book will permanently alter the way we look at our brains, human nature and human potential. A recommended read!



Aiden's Story

Kelly Dicketts
<http://thelionssecret.wordpress.com/>

The Lion’s Secret is a children’s book telling the story of a brave lion with epilepsy and how he shares his secret about his condition with his friends.

In 2008 at 9 months of age, Kelly’s son Aiden was diagnosed with epilepsy. As new parents this was absolutely the most terrifying time of their lives. After coming to terms with

his diagnosis Kelly decided she couldn’t just sit back and do nothing and since she couldn’t take Aiden’s epilepsy away she decided to do everything she could to raise awareness. She has been fundraising for Epilepsy Queensland for over 2 years to raise awareness and education for people living with epilepsy. Aiden is 3 now and has been seizure free for over 2 years but Kelly knows not everyone is as lucky as him. This book is her way of helping Aiden to be understood and accepted, something every parent wants for their child. Kelly’s goal is to donate \$2 from every book to Epilepsy Queensland.

Kelly is self publishing and the book is almost ready for print. For information about pricing or to place an order, please email info@divinedesigns.net.au

face2face

Appointed Chief Executive Officer of Epilepsy Tasmania in July 2010, **Reachelle Beasley** brings to the role diverse business experience and a commitment to community service.

We welcome Reachelle to the Australian epilepsy movement.



Married to Warwick, we have two beautiful daughters, Mahala (7) and Anjali (2), and as a family we enjoy spending time outdoors. I like to think of myself as a keen cyclist (I am no Marion Clignet), but I admit I do wear lycra and drink coffee at the local cafe with my bike outside (yes I am one of those cyclists!).

After studying at the University of Tasmania, Warwick and I bought a hotel in Launceston. I think I can still claim to have been “the youngest licensee in Tasmania” at 21! Running the hotel for five years provided me with a wide range of skills including knowing how to make a great cocktail, how to carry 4 coffees at once and also how to manage a team of 40+ staff in an ever changing and challenging market. With my interest in business, I secured a position on the Launceston Chamber of Commerce Board and also served as both treasurer and chairman of Launceston’s promotion organisation, CityProm.

During this time I was very fortunate to be selected for a Rotary Group Study Exchange to Kentucky, USA. From this wonderful experience, and my desire to do more for the community, I joined the Rotary Club of Central Launceston. I am currently on the board as the international director. I am also a board member with Cystic Fibrosis Tasmania and the Tasmanian nominee for the National Body, Cystic Fibrosis Australia.

Past experience includes consultant to small businesses and working with a large engineering company. After taking some time off work to enjoy being “just mum”, I returned to the workforce as CEO of Epilepsy

Tasmania in July 2010.

Known to throw myself into work and problem solving – life, and its myriad of twists and turns dictated that joining epilepsy was to be no different. But what an introduction! The evening of my second day I was knocked unconscious by my 2 year old jumping up out of the cot. In one of life’s ironies, when the ambulance arrived, the first question the “ambo” asked of my husband was “does she have epilepsy.” He did not take it too kindly when my husband laughed at him. It was not till sometime later that we managed to share the coincidence, and laugh about it.

As a result of this injury, I had a cerebral spinal fluid leak, and was rushed to neurology in Hobart. And so began my introduction into the neurological services in Tasmania, albeit from the incorrect side of the bed. I had an EEG; going through its results at length. As we creep closer to the anniversary of these events I still suffer from some of the side effects associated with a head injury, but what a hands-on introduction into some of the key areas that our clients experience.

Until my appointment I did not know anyone who had epilepsy. I had the preconceived idea that epilepsy was a simple condition that makes people have fits. I really had no idea how vast epilepsy was or how many people were affected. I was completely unaware about the different types of seizures and to be honest if someone told me they had epilepsy and all they did was stare into space I perhaps may not have believed them.

At Epilepsy Tasmania we face

challenges similar to our mainland counterparts: long waiting lists to see neurologists, issues around funding, and the challenge to break down the ever-present stigma of epilepsy. I have met so many people with, or connected to, epilepsy who don’t inform their social circle that they have it. Epilepsy Tasmania needs to lead the way in providing an environment where stigma is minimised, so that people who have been diagnosed with epilepsy feel comfortable to talk about it with their friends, families and work colleagues. Education and awareness are one of my primary goals for Epilepsy Tasmania and I am focused on making a difference.

I am working towards creating an organisation that is stable, has longevity and employs a team of experienced and dedicated professionals to deliver the service. I see Epilepsy Tasmania becoming an employer of choice and this will add additional professionals to our team, which will benefit all who utilise our services.

I embrace technology and the National Broadband Network (NBN) opens doors for Epilepsy Tasmania to be a national leader in the creative use of technology in the provision of delivering services to our rural community.

I have a great team and I see nothing but a bright future for Epilepsy Tasmania.





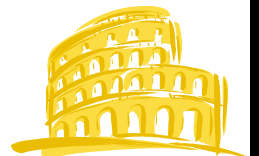
International Bureau
for Epilepsy

1961 - 2011

50 years focussed on epilepsy



29th International
Epilepsy Congress



ROME 2011



28th August - 1st September