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

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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 via social networks facebook and twitter, while supporters in support our work.

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

Keith Chapman
Editor

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Highlights from Melbourne congress

Epilepsy & Society symposium

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.

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.

Highlights from 8th AOEC Melbourne

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Epilepsy Practitioners Forum, Melbourne
The Stigma of Epilepsy and its Impact
Graham Scambler, Professor of Medical Sociology, University College London, UK

neglective 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 that they have epilepsy, it seems they often become defensive; they fear the worst. It is a label they see as threatening to make them ashamed, to reduce them to their epileptic self, to make others treat them differently. 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’ with experts I possess begins and ends. Lewis (2009), whose exploits were like many in my own career, me as all eyes fastened on him. He recounted his personal experiences with great eloquence, and they too seemed to occur in the narrative of the hidden 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. One 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 ‘finding’ that is, 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-umbatient into ‘an epileptic’, as it were, like it or not. Beach, 1989). The presence of the requisite mechanisms need not lead to medical, social and self-labeling if a physician is not consulted or they fail a full diagnosis: 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 dermenting under this diagnostic umbrella, and their division into types and subtypes, continues to be re-assessed. The evolution of diagnostic categories and definitions of epilepsy, in other words, are themselves worthy of sociological investigation. Science and medicine in both pure and applied forms are ‘social constructed’, that is, produced off social processes, 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 epilepsy, as was my own early experience, is more likely than those from high-income families to affect accidents in the home, nearhood and workplace (perhaps a function of to-day’s society, in 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/epilepsy, is 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 the elderly may be 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 own homes, their knit family or other networks, or with the engagement of complementary or alternative practitioners. A fourth dynamic is that between physician/patient and patient/physicians. 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’ with experts, but this does not have to be the kind of ‘fighting back’ epitomized in the activities of Wally Lewis and many, many others.

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Memory – A marvel of nature

Dr David Weintraub
Senior Clinical Neuropsychologist, Department of Neuropsychology, Austin Health, Melbourne

As with walking and breathing, we often take our memory for granted and barely spend time marvelling at the remarkable abilities 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 talk all about 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 the 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.

In humans, memory ranges from simple (‘his name is David’) to the astonishingly complex (‘she can recite all Shakespeare’s poems) to the spatial (‘How do I get … to the hospital?’), from the affective (‘What does it feel like to be drunk?’) to the declarative (‘How much was I paid last?’), from the visual (‘What is the chemical formula for NaCl?’) to the auditory (‘What was the first word that came to mind?’), from the simple (‘his name is David’) to complex (‘the missile was launched from point A to point B which is at a distance of X miles from the launch site’), from the non-conscious (‘I was able to remember the names of the doctors who met me after my surgery, but not who the surgeon was’), to the conscious (‘I was able to recall the names of the doctors who met me after my surgery’), from the non-declarative (‘I can’t kick a football even without thinking about it.’) to the declarative (‘I used to play football every day.’), from the non-spontaneous (‘I was unable to recall the names of the doctors who met me after my surgery’) to the spontaneous (‘I was able to recall the names of the doctors who met me after my surgery’), from the non-prospective (‘I can’t kick a football even without thinking about it.’), to the prospective (‘I will play football tomorrow’).

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. Notwithstanding, as 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 that is 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 to understand how the brain makes memory possible. This is because in TLE, epilepsy and memory co-habitate 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 understanding the neural mechanisms of human memory.” (Snyder, 1997).

The hippocampus

Intriguingly, H.M., a singularly specific to the domain of recent memory. His intellect, his personality, his ability to negotiate the niceties of social interaction, and his habits and emotional predispositions are unremarkable. Yet for him, 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 are part of 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. Because these memories are inextricably bound up with a specific time, place, and emotional state in the individual’s life history, and, the amalgamation 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 girl from California who was really nice. The company was very enjoyable is a form of episodic memory. It provides, in other words, an autobiographical framework within which we locate our past experiences and activities and the time and context in which they occurred. This is what most of us mean by memory – so it seems.

2. 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 subsequently recall facts and declarative memory is a crucial building block for declarative memory. That is, we are able to think about these sorts of memories, talk about them, and manipulate them in the spotlight of full consciousness that is the ‘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 the day my bicycle was stolen.

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 ‘DEF’ and was later given the stem ‘DEF’ and asked to complete it with the first word that came to mind, he would respond with the word shown earlier. If asked whether he’d seen the word ‘DEF’ beforehand, he’d deny any such memory. Similarly, after repeated exposure, he became faster at recognising incomplete line drawings even though he had no memory for seeing the drawing previously. These observations underlined 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.

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and that you felt very sad when you
of memory without remembering the
'testify', the usual colour of a banana,
knowledge of the meaning of the word
in which the memory was formed.
Moreover, it encompasses, for example, our
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 episodic anomaly
Semantic memory is the kind of memory that enables us to store general information about the world and to access it whenever we need it. For example, we can recall the layout of our local supermarket; we can remember the capital cities of the world; we can know what a banana tastes like. All of these are examples of semantic memory.

Episodic memory, on the other hand, is the kind of memory that enables us to remember specific events in our own personal history. For example, we can recall the layout of our local supermarket, the capital cities of the world, and what a banana tastes like. All of these are examples of semantic memory.

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. for nearly 40 years he could recollect, 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 attempt to describe memory impairment tends to be very much milder than that of H.M.

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

The nature of forgetting in TLE
The paradox of H.M. is that through his terrible clinical history he has 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 had undergone unilateral resections of one temporal lobe only. These patients also showed memory impairments, albeit 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. In H.M. a left-sided operation was required 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 passage, however, the kinds of things people with temporal lobe epilepsy tend to struggle with include:

- **Left temporal lobe epilepsy:**
  - **Hippocampal amnesia (HMA):** retrograde memory impairment, or normal or limited – e.g., it cannot deal with more than one or two sentences at a time and its contents decay rapidly to the point of being lost. In contrast, the declarative memory system 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 task is completed, you 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 significantly more demanding 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.

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 content, is semantic or episodic, declarative or non-declarative. However, memories can also be distinguished in terms of the time interval across which the information needs to be remembered. For example, one might consider the 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. It falls under the wider umbrella of working memory and is not limited – e.g., it cannot deal with more than one or two sentences at a time and its contents decay rapidly to the point of being lost. In contrast, the declarative memory system 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
sudden Un(expected) Death in epilepsy (SUDEP) is not a recent phenomenon but historically, when treatments rarely provided good seizure control, death was the main and sometimes quite significant, with this interfering with attention and memory and being the most common cause of non-accidental death. The identification of possible risk factors for SUDEP through epidemiological research has eased the need to discuss this aspect of outcome. We should now take care to make patient discussions can now take on the character of a personalised risk assessment. Risk factors can be identified and with ongoing seizures the patient may seek to reduce risk factors. 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 to achieve 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 have to fear 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 readiness of internet information which is often not correct and certainly not tailored to the individual circumstances of the reader. Personal discussion with their 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 UK study in a paediatric setting found that 91% of parents studied, expected their doctor to provide SUDEP information, and that they had not received it. A Digram 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 and the uncertainty when the diagnosis is explained. Compliance about medication adherence is a common problem in epilepsy. Also, life circumstances can change and may be a more effective way of stopping an epilepsy-related death. For the elderly, risk factors that have 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 their ability to manage their health issues. In settings where risk factors introduced to epilepsy patients it would be advantageous to provide additional support workers, to allow for extended discussion and support. 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 on epilepsy care published in the UK recommend a discussion of SUDEP as part of general epilepsy information and something to be discussed at diagnosis and on every visit. Information about seizures and their impact is provided as part of antiepileptic drug treatment. In the US an epilepsy taskforce is looking at the priorities for a public health approach. The Picture blueprint includes a special focus on SUDEP. The epidemiology of risk factors underlines the need to strive for as good seizure control as possible in all epilepsy patients and this is a very positive influence on epilepsy care worldwide.
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 at the time of the seizure. 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 psychotic 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 antipsychotic 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 behavioural 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 brain can lose control of this 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 seizures 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.

References


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 while 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 the holy grail of epilepsy therapy. Predicting seizures is sort of the ultimate in 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 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 red. When we 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 were 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 constant 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 hinge-like arm which is within arm’s reach during the night. These times are 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 my 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 some 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 text alert 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 for example they are safe, notify others, or the possibility of taking a fast-acting drug to prevent it.
Celebrating Purple Day 2011

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!
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 Philibin, 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 (hemiconic), 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 Dietitian 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.
Incontinence is individual to each person and the person’s age, health profile, and bowel function may be affected by other health conditions which commonly carry incontinence implications. Some antiepileptic drugs, antidepressants, and antipsychotics can cause incontinence. 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 especially important for people with bladder and bowel problems. 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: an over-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) and high in warmth 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. To combat 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 aid in daily life can be a form of “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 bed in heat wave and with higher exercise levels too”.

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 builds a strong core and pelvic floor muscles, which is important in maintaining a continence problem. As part of a general exercise plan, customised to suit the individual person. The issues highlighted by this

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 is people with 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/neuropsychological.

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 comorbidity and 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. The primary 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) remains a matter of considerable research and management possibilities – generally advised by health professionals involved in the care of people with epilepsy.

The cornerstone of incontinence management advice – and not merely “pad up and bed in heat wave and with higher exercise levels too”.

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.

Atitudinal 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 either 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 disturbances and incontinence 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 an important 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 – it’s never too early either: a so-called “first” 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 slippiness of 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 does not always need to 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 of physical, mental and emotional considerations in the maximising of a person’s quality of life.

References


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, incontinence and urgency. Product information includes advice about choice of continence products, suppliers, and eligibility and the application process for federal 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.bladderandbowel.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 was the first to move into the healthcare spotlight. He began doctoral studies looking at men with epilepsy and their challenges with Subjective Well-Being (SWB) following elective neurosurgery for Adult Onset Seizures (AOS). He 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 the smallest 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 PhD 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 operation 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 PhD 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.raffiele@gmail.com

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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 an 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 (7%) or more than instructed (85%), NPS clinical adviser, Dr Danielle Stowasser says taking a casual approach is never a good idea.

“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 involved in their medicines decisions, so they get the most out of them and recognising the role of the pharmacist in engaging, explaining and empowering patients to get the best results from medicines,” she said.

“Every medicine you take should come with clear instructions, including things like 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%).

“Ask 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.

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“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.

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 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 to 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 signing and 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 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.

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**A Great Place For a Seizure**
Terry Tracey
CreateSpace
ISBN: 978-1453834701

“A Great Place For A Seizure,” a debut novel by author Terry Tracey, gives readers a glimpse of life with epilepsy. Mischa Dunn’s family leaves Chile in the wake of the 1973 coup d’état 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, Tracey 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 Tracey’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. Tracey 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: 978-1921327242

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 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 career trajectories change.

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 inspire and motivate people to improve their lives. It will inspire scientists to research and doctors to treat patients. It will inspire teachers to teach kids and parents to teach their kids. It will inspire anyone with a disability to overcome their condition. It will inspire anyone who knows someone with a disability to help them overcome their condition.

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!).

A new study 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 I found out we were supposed 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.