Luke Quinlivan & Riley Elson  
Raising awareness!

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Welcome to the latest edition of The Epilepsy Report. Our national awareness campaign challenging public perception and stigma of epilepsy was launched at the beginning of March, national epilepsy awareness month, and featured Australian water polo goal keeper, Luke Quinlivan, himself a person with epilepsy, gaining extensive media coverage. We greatly appreciate Luke’s commitment to improving public perception of epilepsy. We thank Janssen-Cilag Pty Ltd, UCB Australia Pty Ltd, Sanofi Australia & New Zealand, and GlaxoSmithKline Australia, for their generous support for this campaign. Also contributing to raising awareness of epilepsy and for the work that we do throughout Australia is model and reality TV winner, Nathan Jolliffe. Through his appearance on Celebrity Apprentice Australia, and subsequent media opportunities where he has taken every opportunity to speak out about epilepsy, Nathan has contributed greatly to our awareness campaign. Also in this issue we meet a group of amazing kids who have shown by example that epilepsy is not something to be embarrassed about. Proud to be Purple Day Heroes they have become beacons for a future free of stigma.

We congratulate Martin Raffaele, Australia’s 2012 recipient of the Outstanding Person with Epilepsy Award. Martin’s inspiring story celebrates how achievement and courage walk side by side with epilepsy. Social research informs government and policy makers and ultimately makes a difference in the lives of all living with epilepsy. We encourage everyone living with epilepsy to join the Australian Research Epilepsy Register, participate in the Longitudinal Study of the impact of epilepsy, and help change the future.

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Martin Raffaele
Australia’s recipient of the IBE’s ‘Outstanding Person with Epilepsy Award’ for 2012

The Joint Epilepsy Council of Australia is pleased to announce the Australian recipient of the Outstanding Person with Epilepsy Award for 2012 is Martin Raffaele.

This award, presented by the International Bureau for Epilepsy (IBE) every two years at the Asian & Oceanian Epilepsy Congress, recognizes:

• Contribution to community service for people with epilepsy;
• Longstanding support for people with epilepsy;
• Longstanding advocate for people with epilepsy (community, disability, politics, media);
• Individual achievement that inspires others (personal, professional, educational, sporting, creative) regardless of their epilepsy;
• Distinguished service to a local epilepsy support organization.

From the nominations received, the Joint Epilepsy Council of Australia, chose Martin Raffaele of New South Wales to receive this award.

Martin has lived with seizures for most of his life, although his epilepsy, caused by complicated febrile convulsions, was not properly diagnosed until his early 20s, when after years of aura, he started to experience complex partial seizures. A promising professional/operatic singer in receipt of many scholarships from the age of 15, he found the scholarships discontinued not long after he began experiencing regular seizures cutting short a promising career. Martin tried many jobs but was unable to keep them due to the frequency of his seizures and was forced to accept a disability pension. Not wanting to allow his epilepsy to take control, in 1998 at 26, he began tertiary studies, however the frequency of his seizures led him to undergo partial temporal lobectomy in 1998. Six months later he recommenced his studies at Sydney University however his seizures returned and in October 2000, he underwent a second partial temporal lobectomy. Through two operations and periods of recovery, it took Martin 7½ years to complete his Bachelor of Arts (Sociology) degree in 2005. He has since completed a MPhil (2009) investigating the misdiagnosis of Childhood Absence Epilepsy as Attention Deficit Hyperactivity Disorder (ADHD), and in 2010 commenced his PhD thesis ‘Subjective Well-Being (SWB) in men with neurosurgery for Adult Onset Epileptic Seizures (AOES).’

In August 2010 Martin was the recipient of an Australian Postgraduate Award. This Scholarship is presented to students with exceptional research potential. During his time studying, Martin has conducted a support group for men and worked as a volunteer counsellor. He has presented his research at various conferences held in Australia and in 2011 Martin volunteered to speak about his epilepsy and experience for the Epilepsy Australia Keeping Epilepsy in Mind PR Campaign where he was interviewed on live radio, and by journalists for print media. Martin has been a willing, unofficial ambassador for Epilepsy Australia since 2008, speaking about his experience with epilepsy.

Martin continues to have seizures; his operations while successful in reducing the frequency of his seizures has not controlled them and he remains on a disability pension.

Determined not to let his epilepsy control him, Martin takes risks everyday living in the inner-city of Sydney, using public transport, both trains and buses, to travel alone to university to pursue his studies. Martin believes that there is a need to better understand the impact of epilepsy and surgery from a male perspective and how men go about re-establishing their lives and place in society. Martin battles with the unpredictability of seizures on a daily basis.

Accompanying this award was a small travel bursary to travel to Manila to accept the award. Martin courageously travelled to Manila on his own knowing he could have a seizure at any time. He proudly accepted his award from Mr Mike Glynn, President of IBE, at the opening ceremony of the 9th Asian & Oceanian Epilepsy Congress. The 2012 recipients from across the regions awarded in Manila were:

• Ms Yashoda Wakanark, India
• Mr Baldwin Chua Kho, Philippines
• Mr Purniyaw Tsoagtaan, Mongolia
• Mr Fai Ming Hung, Hong Kong
• Ms Yung-Chih Chen, Taiwan
• Mr Hongquan Li, China

Martin also had a poster on his research study accepted for this scientific meeting.

From all of us at Epilepsy Australia, we congratulate Martin on this well-deserved award.
Telehealth - bridging the miles

by Rosey Panelli

Telehealth consultations provide an opportunity for patients to meet with their specialist health providers using video technology and from 1 July 2011 the Australian Government began to provide Medicare and Department of Veteran Affairs (DVA) rebates and incentives to promote this style of service provision in areas outside the designated inner metropolitan sector. Patients who are residents at aged care facilities, or who are receiving health services at an eligible Aboriginal Medical Service qualify to receive funded Telehealth services anywhere in Australia. Consultations can be provided by specialists, consultant physicians and psychiatrists. Rebates also enable general practitioners (GPs), other medical practitioners, nurse practitioners, midwives, Aboriginal health workers and practice nurses to provide clinical assistance to the patient during the specialist video consultation (1-3). The potential benefits to patients who can access their specialist via Telehealth consultations are immediately apparent. Time lost from work due to long distance travel, the costs of travel, and sometimes the expense of accommodation can be greatly reduced. For patients with epilepsy, reducing the need to travel far from home is especially helpful as they are frequently subject to periods of time when driving is prohibited. If they cannot drive themselves, and if private transport is the only way to reach their specialist service provider, the patient is dependent on the availability and generosity of family and friends. Even where public transport is available there can be concerns about the possibility of a seizure on public transport while travelling long distances.

Epilepsy affects approximately 1% of the population and the number of physicians who specialise in epilepsy care is relatively small. Most are located in the major Australian cities in association with epilepsy specialist care centres and where patients cannot travel easily their choice of service provider is limited. There can be pressure to select specialist care based on locality rather than expertise in epilepsy, but having access to Telehealth can facilitate more equitable and appropriate access to care. Easy access to an epilepsy specialist through Telehealth has given great peace of mind to epilepsy patient Victoria, although she is an active woman and still able to drive, she is not confident to tackle the journey to Melbourne by car and is wary of having seizures on the train or moving about in the city. She feels fortunate that her epileptologist Professor Terence O'Brien is pleased to consult with her using video conferencing. Professor O'Brien has found that Telehealth offers an excellent resource for improving service delivery to people with epilepsy. 'Sometimes I have patients who drive six hours to see me for just fifteen minutes as they travel around and drive home again. I know this is a huge effort for them and it concerns me, but I can't go to them' he says. 'For specialists I think it will reduce some of the barriers they might feel to reviewing patients regularly, because it removes some of the logistical issues.' Despite his enthusiasm for the concept Professor O'Brien still requests patients to visit personally for their first appointment, preferring face to face meetings for the initial assessment, and electing to utilise Telehealth for review visits. 'Telehealth is not the only solution to providing quality epilepsy care but it is a very useful tool in the toolbox as we work to tailor the best possible individual management' he says.

As Telehealth options begin to permeate day-to-day epilepsy care Professor O'Brien is not alone in his concern to balance the convenience of video conferencing with the benefits of face to face meetings. Maintaining good personal interaction is an important aspect of the therapeutic relationship and some health practitioners are concerned that patients might consider the video screen to be creating a barrier to communication, especially if they are older and unfamiliar with the technology. However, satisfied patients like Margot Green suggest that the benefits are strong enough to outweigh any negative factors. Margot is very comfortable with the technology and finds no difficulty communicating via the video link. 'I can see my doctor’s smiling face and he hears me loud and clear so we can chat away just as easily as if we were in the same room,' she says. The enthusiastic response to telemedicine by both Margot and Sarah reflects research findings which indicate that Telehealth is positively regarded by Australian patients. Research also suggests that when considering the full range of Telehealth services operating throughout the country, although there are some potential ethical, medical-legal and governance problems which have arisen they appear to be have been easily managed (4).

Telehealth consultations depend on the enthusiastic cooperation of service providers at both ends of the video link, and Margot Green is fortunate that her local GP at the Seymour Medical Clinic has been quick to embrace the Telehealth concept. Figures indicate that only about 4500 video consultations involving GPs occurred during the first nine months of the program (5), although the Government has an expectation that 495,000 Telehealth consultations will have occurred by July 2015 (6).

Some GPs see benefits in consultations which include both GP and specialist. Patients with a poor memory for example may appreciate direct input into the consultation by their GP and where patients have a complex condition, direct communication between the specialist and the GP can facilitate rapid management decisions which include patient participation. However, in cases where GP participation is not necessary, and where the patient or specialist prefers to have a private meeting, Medicare rebates are flexible enough to allow consultations to be coordinated by the practice nurse.

The slow uptake of telemedicine, despite the healthy rebates, may reflect a lack of clear guidance regarding the program in its early stages (7,8). The Australian Medical Board did not release guidelines for technology-based consultations until January 2012 (9) and the Royal Australian College of General Practice (RACGP) released its addendum to the RACGP Standards for General Practices (4th edition), proposing standards for general practices offering video consultations, in October 2011 (10) There are plans to review the RACGP addendum in October 2013.
2012 and feedback can be sent to the RACGP. Telehealth resources, including a patient information sheet, are also now available from the RACGP (11). Nevertheless when it comes to selecting the equipment appropriate to the task, guidance from all sources has been obscure. Directives highlight the need for a secure link, but no one option may be recommended. For the general practice manager at Seymour Medical Clinic, Gay Mitchell, the hardware choices presented no problems. We use our laptop with a webcam and move it wherever we need it’ says Gay. ‘However, when we were considering the software options we found that although some programs like Skype were not recommended because of security risks, there are doctors who do use it. We decided to pay a fee instead and install the Telstra option which guarantees a secure service, and was a national option that we expected might become generally adopted. However, every doctor we speak to seems to have selected a different system so there is still a great deal of confusion surrounding the choices we might need to make. Something we must check with every specialist we add to our Telehealth list.’ At the Royal Children’s Hospital in Melbourne families who link in to their specialists from their hospital rooms or a GP clinic, are provided with the GoToMeeting software by the hospital for free charge. All patients linked to the hospital have their appointments booked into the hospital calendar by the hospital and pop up reminder messages ensure that nobody forgets a consultation. More information is available from the hospital’s website(12).

Epilepsy patients are enjoying the benefits of Telehealth all over Australia, especially in larger states where the distance to services can be as much as a thousand kilometres. In Queensland Dr Anita Cairns, a paediatric neurologist does weekly Telehealth clinics from the Royal Children’s Hospital to towns such as Mackay or Gladstone. ‘It works well for most epilepsy patients, allowing me to modify medications and doses without the long trip to Brisbane’ she says. ‘I find it helpful to have a local doctor present so that they are aware of the changes I have made to the patient’s care.

Sometimes the consultation can provide enough guidance to the local team in terms of investigations and management that the patient does not need to come to Brisbane. This is an advantage where children have associated behavioural problems, or physical disabilities and air travel is especially challenging for the family.

For clinicians with an interest in Telehealth and a desire to stay abreast with up to date information, the Australian College of Rural and Remote Medicine (ACRRM) has established a specific Telehealth web page (13). The online community has been created for health and medical professionals (generalists and specialists) who are interested in the use of Telehealth to improve access to care for rural, Aboriginal and aged care patients. The site offers a range of resources including a provider directory, a technology directory and regular updates to links and current Telehealth news.

Meanwhile at home in Nhill Sarah Reichelt needs every bit of energy and support she can muster to care for Ethan’s needs. A very busy profession has given up work to care for her son. At the age of two and after four gruelling rounds of neurosurgeries, Ethan still suffers from seizures. ‘On a good day he might have four says Sarah, but a bad day it can be sixteen. He is on a trial drug now and he needs very careful monitoring. I am so thankful that one in every two meetings with Ethan’s specialist can be done at our kitchen bench.’ Ethan’s epilepsy specialist, Dr Simon Harvey is also pleased with Telehealth. ‘The technology does not have to be complicated or expensive’, he says. ‘A simple USB microphone and camera plugged into the desktop, or a laptop with built in camera, plus a reasonable internet connection, serves the purpose. The concept is well suited to epilepsy management, where there is often limited need to examine patients and main requirement is to discuss issues such as seizures, medication side effects, behaviour, and development. I also use video meetings to follow up with interstate patients and to discuss patients with my interstate colleagues, though the Medicare Telehealth funding does not apply in this setting’.

From the patient perspective it would appear that Telehealth has received a resounding vote of approval, although the uptake by health practitioners has so far been modest. As information about the service spreads through the community it seems likely that there will be a strong will demand for rapid development of this new health care alternative. The Epilepsy Report welcomes comments on this topic from both health care providers and consumers.


Reducing Epilepsy Death (RED) Project

The Reducing Epilepsy Deaths (RED) project, established to investigate a range of issues associated with epilepsy-related death in Australia continues to progress in 2012.

One key area of activity is to examine the experiences of those bereaved by epilepsy. A pilot study has now been completed and Dr Michelle Bellon of Flinders University has joined with Dr Rosey Panelli to take this important work to the next stage. The data will be gathered using an online questionnaire. The study has recently received ethics approval and details about how to participate in the survey will soon be available on the Epilepsy Australia website.

As the RED project has progressed an extensive bibliography has been created and this will soon become available online for those who have access to Endnote web. Whilst the other aspects of the project including the study of the National Coroner’s Information System (NCIS) continue to move forward, progress has been restricted by lack of funding. Several applications have been put forward to government and philanthropic institutions seeking support for this important activity.

The online survey of GPs in Australia and New Zealand proved very useful and the data collected is contributing to the development of quality support for general practice in Australia. During the survey four random incentive prizes were offered thanks to the generous support of 3M Medical. One GP from New Zealand and three GPs from Australia were lucky enough to win a 3M Littmann Electronic Stethoscope Model 3200 (www.littman.com.au).

Epilepsy Australia thanks all GPs who took the time to assist us with the survey and congratulates Dr Linda Mellor (Wellington, NZ), Dr Bradley Forsman (NSW), Dr Gary Bourke (Bendigo), and Dr Peter Davies (Launceston). The work of Epilepsy Australia to improve awareness and action on epilepsy-related death continues to receive international acknowledgement. In June Dr Rosey Panelli, coordinator of the RED project attended the first Partners Against Mortality in Epilepsy Conference (PAME) in the US. She presented on education as a prevention tool.

Epilepsy & Society Symposium, AOEC, Manila

SUDEP was one of four topics for the Epilepsy & Society Symposium at the 9th AOEC held in Manila in March. From Alava from the Philippines gave a very clear presentation on What is SUDEP? Denise Chapman (pictured above) reviewed the rise of global advocacy of SUDEP over the past 15 years: the milestones shared, the challenges that still lay ahead. Her participation was by invitation.

In 2012, Epilepsy Australia established the SUDEP Research & Education Fund. The purpose of this Fund is to advance our knowledge of epilepsy-related death through undertaking or facilitating research and to provide community education on epilepsy-related risks.

This Fund receives donations from families, friends and colleagues who have lost a loved one to epilepsy, and philanthropic organisations dedicated to epilepsy research.

To date this Fund has supported the work of the Reducing Epilepsy Death (RED) Project and funded the local printing and distribution of the publication Sudden Unexpected Death in Epilepsy: continuing the global conversation.

With heavy heart...

In the December 2011 issue of The Epilepsy Report, the Outram family was featured in the story ‘Happy Endings’, where we reported the safe arrival of baby Oscar, after mum Katherine’s seizure prone pregnancy.

I regret to advise our readers that Katherine, 27, passed away on Saturday, 10 March 2012, from SUDEP. Our deepest sympathies are with her husband Drew and baby Oscar, and their families, as they come to terms with their tragic loss.
Have we used antiepileptic drugs incorrectly?

Professor Frank Vajda

There are two aspects of antiepileptic therapy that need emphasis and increased recognition – the individualisation of treatment, and dose issues. Reviewing our practice in the use of antiepileptic drugs (AEDs) in the treatment of epilepsy over the past decades, these points need to be highlighted, and although not new, they have not been embraced by all practitioners.

Drugs, that have a low therapeutic index, a feature characteristic of AEDs, imply that the dose required to exert a beneficial effect, i.e. to control seizures, is not very different from doses that cause toxicity.

Hence we need to be aware that unnecessarily high doses of AEDs are potentially dangerous. This is true not only because it results in severe toxicity, but also because even mild drug related symptoms may cause patients abandon medications, becoming non-compliant and thus defeating the purpose of prescribing drugs at all.

If a drug is generally well tolerated, such as valproate (Epilim), it has been accepted for decades, both by specialists and general practitioners, to prescribe for adult patients in a standard dose and for general practitioners, to prescribe for adult patients in a standard dose and for general practitioners, to prescribe for adult patients in a standard dose.

The rash is also more likely to occur in patients with epilepsy, the epilepsy syndrome, past history of response to an individual drug, the age and gender of the patient, renal function, concomitant medications prescribed, for example, for cardiac disease, or intolerance to a known class of drugs.

Individualisation according to age is well established. The above list is only a partial compilation of possibilities that affect the decision on how to prescribe AEDs, and to make allowances for individual variations in drug response.

Patients with well diagnosed epilepsy, especially those with convulsive seizures must be treated, in order to reduce the risk of sudden unexpected death in epilepsy (SUDEP), which is the ultimate harm that may befall a patient with epilepsy and their families.

In order to maintain a good quality of life on antiepileptic drug treatment, individualisation of therapy and awareness of dose-related complications must always be kept in focus.

References

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In pregnancy however lamotrigine elimination is enhanced by the sex hormones, so that doses of lamotrigine must be increased every 13 weeks, and returned to baseline doses, after the baby is born.

The oral contraceptive pill also affects lamotrigine concentration, which complicates the fact that each individual has a characteristic therapeutic window, or range, for lamotrigine and population derived therapeutic ranges are a spurious concept and do not help management.

Individualisation of doses on the basis of the above is not sufficient.

Account must be taken of the type of epilepsy, the epilepsy syndrome, past history of response to an individual drug, and the age and gender of the patient, renal function, concomitant medications prescribed, for example, for cardiac disease, or intolerance to a known class of drugs.
Raising the profile of epilepsy in the ACT

It wasn’t really an orthodox use of work time, but Jacinta Cummins was planning to sneak out of her office for an hour or so last week to help an Epilepsy ACT member finish off a mammoth houseclean.

Some of my things aren’t quite ‘normal stuff’ but I think they’re needed for people they just give them that kickstart,” the Epilepsy ACT executive director explains.

The man Jacinta was going to help had been unwell for decades before medication changes led to a dramatic reduction in his epileptic seizures and an end to a prescription drug-induced foginess.

“Until 17 months ago he had been living in a foggy world and he finally found a neurologist who’d listen to him.

“The neurologist took him off a lot of meds and it’s amazing, this last 17 months he’s started becoming his own person.

“He’s never been able to work, he’s never been able to drive because of his seizures. He even found it difficult to walk his kids to school."

The man may soon be able to apply for a driver’s licence and look for a part-time job.

He has taken advantage of his new energy by throwing himself into housecleaning, cooking and completing parenting courses.

“He’s really, really trying to come back into the community again,” Jacinta says.

Jacinta’s office is a former science laboratory on the first floor of the old school now called the Grant Cameron Community Centre in Holder. She is joined every day by volunteer Elizabeth O’Brien who has dedicated herself to Epilepsy ACT after retiring from a career in special education and also works with a core group of about 30 other volunteers.

From a desk by the window Jacinta offers information and advice to anybody who has been told by their doctor that they have joined about 5000Canberrans living with epilepsy, their families and the community in the ACT and surrounding areas.

Services offered include counselling and support, community education, advocacy, and training in the management of epilepsy.

For more information about Epilepsy ACT go to www.epilepsyact.org.au or call 02 6287 4555

Seeking to raise the profile of epilepsy in the ACT, Peter Jean, from the Canberra Times, met with Epilepsy ACT executive director Jacinta Cummins, to find out more about epilepsy and Epilepsy ACT.

Formed in 1981, Epilepsy ACT provides services for the 5000Canberrans living with epilepsy, their families and the community in the ACT and surrounding areas.

Services offered include counselling and support, community education, advocacy, and training in the management of epilepsy.

...and Jacinta warned him that he would need to move into a bigger property when the baby was born. But a shortage of properties meant public housing authorities were unable to help.

When the baby was born he didn’t get enough sleep and he started back with seizures.

“So we took it all the way up through Housing and got to the last point and then they gave them a house that afternoon.

They got him into the house and now everything’s in order, and he gets enough sleep, he’s buying his own house, holding down a job.

“Sometimes simple interventions can stop bad things from happening.”

Jacinta clearly loves her job.

“I think you get addicted to community work,” she says.

As long I think I’m doing something right (which I think I am) and as long as there’s a new challenge in front that I think I can meet, then I’ll keep on going.”

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Remembering Adam

The Adam Fry Memorial football match, auspiced by Tuggeranong United Football Club, took place again this year in March. Launching the new football season, the day raised awareness of epilepsy and funds for Epilepsy ACT. Congratulations to State League Division 10 for taking out the Adam Fry Memorial Shield for 2012.
Standing up for epilepsy

Nathan Jolliffe

Nathan Jolliffe, won the hearts of all Australians living with epilepsy, when he chose to represent Epilepsy Australia in the latest series of Celebrity Apprentice Australia. By talking frankly about the impact epilepsy had on him as a child, and the social anxiety that still lingers, Nathan brought epilepsy to a national audience, giving great encouragement to all people living with epilepsy.

A confident, articulate and laid-back lad, it was Nathan’s determination, intelligence and mettle that saw him, along with best mate Tyler, win the Amazing Race Australia in 2011, and allowed him to overcome the big personalities on Celebrity Apprentice Australia raising $30,000 for Epilepsy Australia along the way.

Yet Nathan reveals a vulnerable side when he talks about having seizures as a child. “I was very embarrassed about it, and I think there are a lot of kids who are,” says Nathan. “When I had a seizure it would happen at night, about half an hour after going to bed. It definitely stopped me from doing a lot of things, and felt like I was going to swallow my tongue, then the seizure would take me away,” explains Nathan.

Nathan also speaks candidly about the hint of anxiety that sets in when he thinks about seizures today. “It’s the most horrible thing in the world when you have lost complete control of your body.”

“I was frightened of having a seizure. Sleepovers would be fine until about an hour after going to bed. It definitely stopped me from doing a lot of things, because I was frightened of having a seizure. Sleepovers would be fine until it was time to go to bed and then I would be so scared I’d have a seizure, I would have to call my parents to come and get me. School camps were another experienced missed because I was embarrassed and didn’t want them calling my name to come and take my medication.”

Diagnosed at the age of six with Benign Rolandic Epilepsy, an epilepsy of childhood that is generally outgrown by the teenage years, Nathan had around a dozen seizures (even while taking antiepileptic medication) until he was 13, when the seizures stopped. Now 26, the memory of seizures remains.

It’s hard to explain what it feels like when a seizure comes on – everyone is different – but mine affected my speech, and felt like I was going to swallow my tongue, then the seizure would take me away,” explains Nathan.

After competing in The Amazing Race Australia I learnt a lot about myself. The things I put my body through – hunger, sleep-deprivation, stress, pushing myself to the limit – all the things that could trigger a seizure and I thought if ever I am going to have a seizure again, it would have happened then and it didn’t.

“I was very embarrassed about it, and I think there are a lot of kids who are,” says Nathan. “When I had a seizure it would happen at night, about half an hour after going to bed. It definitely stopped me from doing a lot of things, because I was frightened of having a seizure. Sleepovers would be fine until it was time to go to bed and then I would be so scared I’d have a seizure, I would have to call my parents to come and get me. School camps were another experienced missed because I was embarrassed and didn’t want them calling my name to come and take my medication.”

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Nathan made it to the final, where he competed against Ian ‘Dicko’ Dickson for the title of Celebrity Apprentice Australia 2012. While Dicko won the final challenge and the winner’s prize of $100,000, he generously shared the prize with Nathan, commenting “after the race Nathan ran, he deserved half of it!”

With Dicko’s generous gift of $50,000, Nathan’s appearance on Celebrity Apprentice Australia raised an amazing $80,000 for Epilepsy Australia!

When water polo champion and Olympic hopeful Luke Quinlivan had a seizure in the diving pool at Challenge Stadium in Perth in November 2010, it was a very ‘scary’ reminder that he had epilepsy.

As his teammates watched in amusement, thinking he was mucking around, Luke, in a ‘strange’ stretching pose’ was seizing on the bottom of the pool, seconds away from drowning. Realizing something was wrong, his cousin Nick O’Halloran and best mate Mitchel Ainsworth quickly swam down to Luke, who had been under water for about 60 seconds, and heaved their 100kg teammate out of the pool.

“...the hint of anxiety that sets in when you have lost complete control of your body.”

When I woke up there were people looking over me and a pool attendant pushing an oxygen mask on to my face and people pushing me to sit down,” remembers Luke when asked about the event today.

“I didn’t know where I was or what was going on, so my natural reaction was to try to fight people off. It felt like I was being attacked.”

Taken to hospital for observation, Luke made a full recovery. Luke blamed the seizure on missing his usual morning dose of medication for epilepsy.

Luke was diagnosed with epilepsy in 2001 at the age of 15.

“I know on a conscious level that I have epilepsy and asthma and no hearing in my left ear, and that I’m short-sighted, but on a subconscious level I don’t accept that I have (any problems) and I just get on with it,” says Luke.

“That’s a good thing in the sense that I’ve never been afraid ... but it’s also been my downfall because there are moments when I have been lax and forgotten to take my medication.”

“This last seizure (in November 2010) was a harsh reminder that I can’t be complacent.”

And this is the message Luke wants to bring to all young people living with epilepsy – don’t be complacent with your medication.

With his eyes set on a place in the national team for the London Olympics, Luke is training hard. But he also finds time to help raise awareness of epilepsy and dispel some of the myths and stigma surrounding epilepsy by working with Suresh Rajan, CEO Epilepsy WA speaking out about epilepsy, and teaming up with Epilepsy Australia to feature in their latest community service announcement (CSA). Do your best. In this CSA Luke talks about working hard to do his best in the hope of representing Australia in the 2012 Olympics, whilst also addressing the prejudice that people with epilepsy may face from others. The CSA, first aired on national TV during March, National Epilepsy Awareness Month, resonated with many Australians living with epilepsy, and gave hope and encouragement to others not to give up on their dreams.

While Luke admits there has been setbacks, his determination to pursue his ambitions in spite of his condition is proof that people living with epilepsy can go on to achieve great things, overcoming the prejudices towards their condition from the wider public along the way.

For those who have not seen the CSA, it can be viewed at EpilepsyTVAustralia on Youtube.com

Luke has also participated in the ILAE’s Stand Up For Epilepsy Campaign, with Epilepsy Australia submitting a photo of Luke and young Riley Elson from WA to be part of photographic exhibition at the 10th European Congress on Epileptology in London, September 2012.

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With his eyes set on a place in the national team for the London Olympics, Luke is training hard. But he also finds time to help raise awareness of epilepsy and dispel some of the myths and stigma surrounding epilepsy by working with Suresh Rajan, CEO Epilepsy WA speaking out about epilepsy, and teaming up with Epilepsy Australia to feature in their latest community service announcement (CSA). Do your best. In this CSA Luke talks about working hard to do his best in the hope of representing Australia in the 2012 Olympics, whilst also addressing the prejudice that people with epilepsy may face from others. The CSA, first aired on national TV during March, National Epilepsy Awareness Month, resonated with many Australians living with epilepsy, and gave hope and encouragement to others not to give up on their dreams.

While Luke admits there has been setbacks, his determination to pursue his ambitions in spite of his condition is proof that people living with epilepsy can go on to achieve great things, overcoming the prejudices towards their condition from the wider public along the way.

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Purple Day 2012 – young heroes lead the way

Following in Cassidy’s footsteps...

Cassidy Megan started Purple Day in 2008 because she wanted to tell everyone about epilepsy, especially that all seizures are not the same and that people with epilepsy are ordinary people just like everyone else.

She also wanted kids with epilepsy to know that they are not alone.

Now in its 4th year, Purple Day has become a global event, raising awareness of epilepsy in 64 countries over seven continents (yes, even in Ross Island, Antarctica!)

Cassidy’s dream proves the ‘power of one’, and our young Purple Day Heroes, across the country, have shown us how each and every one of them have made a difference.

Celebrating around the country . . .

Riley Elson
Western Australia
Being diagnosed with epilepsy on your 10th birthday isn’t the best birthday present, but Riley took it in his stride. Taking up the challenge to be a Purple Day Hero, Riley, 11, began speaking out that it’s OK to have epilepsy and his message soon caught the attention of local media with interviews on TV and newspaper. With the support of his family, community and school, Riley became Epilepsy Australia’s highest fundraiser, raising $5815.10. As a thank you, a meeting and photo shoot with Luke Quinlivan, Australian water polo goalkeeper and epilepsy spokesperson, was arranged for the ILAE Stand Up For Epilepsy photographic exhibition. Excited to meet his hero, Luke surprised Riley by giving him his Australian team jacket!

Mackenzie Beames
Queensland
Growing up in the small mining town of Tieri, Central Queensland, Mackenzie, 12, is passionate about sport. A ‘mad keen’ footballer, she plays touch football, and is a Brisbane Broncos fanatic. Being diagnosed with epilepsy in 2010, hasn’t stopped Mackenzie from pursuing her love of sport nor does she see epilepsy as a barrier to sporting achievement or her future dreams. Embracing Purple Day, Mackenzie, with support from her home town and her school community, was the highest fundraiser for Epilepsy Queensland, raising the outstanding amount of $13,400. A surprise meeting with her hero, the ‘King’, Wally Lewis, was arranged, with photos also submitted to the ILAE Stand Up For Epilepsy photographic exhibition.

Chris Buttner and Lachlan Bischof-Foster, Victoria
Helping students and teachers better understand epilepsy and seizures, Chris, 10, and Lachlan, 13, speak out about their experience with epilepsy in the Epilepsy Foundation of Victoria’s Epilepsy Smart Schools training DVD. In talking about their individual type of epilepsy and the way they manage it, and their desire to treat the same as other kids, the boys reveal a confidence and maturity beyond their years. EFV, with corporate partner Melbourne Storm Rugby League Club, launched Purple Day at the Storm vs Roosters NRL match at AAMI Stadium. These inspirational lads had the unforgettable experience of running through the banner with Captain Cameron Smith, and onto the ground in front of a crowd of 12,000, as well as momento photos taken with Frank Barrett, GM Communications and the team.

Makayla and Blake Fittler
New South Wales
Wanting to raise funds for epilepsy research so their one-year-old sister, Katie, could be ‘fixed’, Makayla, 7, and Blake, 5, joined our band of Purple Day Heroes and set a fundraising target of $500 for Epilepsy Australia. Both Makayla and Katie have an inherited form of epilepsy from their father, Scott, and while Makayla has been seizure-free for the last three years, little Katie, hasn’t been so lucky with her seizures proving more difficult to control. Living in Lithgow NSW, Makalya and Blake were interviewed for their local newspaper about their wish for Katie, and, with support from mum, Julie, their school, and their local community, exceeded their wildest dreams raising the amazing sum of $1661.40.

Meg Logan
New South Wales
Meg, 11, first learned about Purple Day from our TV advert last year and researched it on the internet. Inspired by Cassidy, Meg decided that she, too, could make a difference. With the support of her school, Hunter School, Meg organised a Purple Day fundraiser to sell the dozens of purple cupcakes and stress balls she made with the help of her mum. Meg was excited to raise $102.70 for Epilepsy Australia, but what made her happier was another student, who was embarrassed about having epilepsy and had kept it a secret, joined in and helped her, asking people to support them both. As Meg said “he wasn’t embarrassed any more.” Meg loves dancing and does not let epilepsy stand in her way, recently participating in Star Struck, where 3000 public school children performed at the Newcastle Entertainment Centre.

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EFV celebrates 6th Memorial Service

Heralded by the peal of the church bell rung by Jeremy Maxwell, 160 people met at St Marks, Camberwell on the 22nd April this year to celebrate the Epilepsy Foundation of Victoria’s Sixth Memorial Service.

Every two years we meet to remember those who have died through epilepsy and to offer support to those who are trying to live with their loss.

Following a welcome by the CEO Graeme Shears, the reading of a message of unity from Epilepsy Bereaved UK and a poem from Philip Brady, the service proceeded with moving reflections from David McLachlan and Janine Mifsud, to Rev Greg Allinson. 106 names of those being remembered were presented by Gillian Davies and Wayne Pfeiffer.

Music is always an important feature of our service and this year the Canterbury Chorale presented beautiful, pure renditions of Faure’s Sanctus and Smile, words by Michael Leunig and music by Kate Sadler, their Musical Director. Kate’s voice also resonated in a soaring solo of Love lifts us up where we belong.

A most moving part of the ceremony was the lighting of memorial candles, by families and friends, during which the 106 names of those being remembered were read by Rev Greg Allinson.

Dr Rosey Panelli, in her address A line in the sand spoke of the historical progress of the acknowledgement of the incidence of SUDEP. She told of the encouraging worldwide attention being given to reducing epilepsy deaths, at the same time reminding us that primarily, research and funding is needed to achieve better control of seizures in order to fulfill this aim.

During the afternoon tea we joined together to drink the traditional toast to those who live on in our memories. Those attending the service, as always, expressed their appreciation of the opportunity to remember their loved ones, amongst others who understand their loss, for it makes them feel less alone.

In the words of John Cafarella who was unable to attend this year, I believe that this event goes a long way in helping to come to terms with losing a loved one to this disease, as you can see that others are as lost as you are and are hurting as you do.

The service closed with the uplifting hymn Morning has Broken, words by the poet Eleanor Farjean, and was followed by afternoon tea at the Foundation where photos, stories and other memorabilia of loved ones, sent by families, were displayed.

The experience has highlighted how beneficial partnerships between international epilepsy organisations can be for both countries. Future joint EFV and NEA outreach epilepsy clinics in West Nepal are planned for September 2013.

EFV celebrates 6th Memorial Service

Nepal is a beautiful country, famous for its stunning Himalaya, rich culture and generous hospitality. In a country that is only 65% the size of Victoria, its population is greater than all of Australia! Yet, there are less than twenty neurologists in the whole country. A significant percentage of people live in poverty, and most people are dependent on agriculture for a living.

For those living with epilepsy, access to specialist support, medication and community understanding of this highly stigmatised condition, life can be very isolating and overwhelming.

A partnership between the Epilepsy Foundation of Victoria (EFV) and the Nepal Epilepsy Association (NEA) has recently seen Janita Keating, Education and Training Manager, EFV and Hemav Rajbandari, Vice President NEA develop and deliver epilepsy education to teachers and health workers in the remote village of Nangi in the Myagdi District of West Nepal.

The training focused on emphasising that epilepsy is a medical condition that should be treated by a doctor (not a shaman or witch doctor); that epilepsy is not contagious; that when correctly diagnosed and treated by the appropriate medications seizures can in 70% of cases be well controlled; seizures are not the result of punishment or bad gods; and how to appropriately support the person during and after a seizure.

Five health workers and thirty teachers attended the sessions, with one health worker walking nine hours by foot to attend! Pictorial resources were distributed to the health workers to better enable them to continue the educative process with newly diagnosed villagers. Linkages with NEA were established, so that any future questions or referrals can be addressed via telemedicine communications.

Sharing training expertise

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Feedback from health workers and teachers was very positive. The experience has highlighted how beneficial partnerships between international epilepsy organisations can be for both countries. Future joint EFV and NEA outreach epilepsy clinics in West Nepal are planned for September 2013.

Changing training expertise
Living with the shadow of epilepsy

Tim Kennaway

My Shadow is the story my father, Tom Kennaway (1936–2011), wrote for me when I was seven – to explain his philosophy for coping with his tonic-clonic (grand mal) epilepsy and life – that “...you must always get straight back up on to your horse after it throws you.”

This book follows the trials of a young cowboy (jackaroo) who faces several setbacks on his way to breaking in and taming his beautiful mare – “Shadow.” Through dogged persistence and a “never give up” attitude the jackaroo triumphs in the end, as my father eventually did over his “shadow” – epilepsy. Tom based My Shadow on the two wonderful years he spent jackaroosing at Brewon Station, near Walgett in NSW, where he became great friends with a spirited horse named “Shadow”.

It was only after my father’s death from cancer in April last year, that it became possible for me to consider publishing My Shadow. Dad and our family kept his epilepsy a secret all his life and we never openly discussed it until after his death, not because of feelings of shame, but mainly due to the negative impact it would have had on his employment. Tom also didn’t want to be treated differently from other people and he wanted to achieve things on his own merit with no special considerations.

The first time I ever told an “outsider” about dad’s epilepsy was when our family was making Tom’s funeral arrangements. The funeral director suggested that we put green ribbon around the nine red roses (representing Tom’s immediate family) that we placed on dad’s coffin before his private burial. I said proudly, “No, we want purple! My dad had epilepsy.” The purple ribbons were a secret tribute from those “in the know!”

Dad experienced his first seizure in his mid-teens for no particular reason. He then had many “fits” over the next eight years. Throughout this period he desperately tried to get his epilepsy under control by adjusting his medication. As a result of his determination and the kind people who helped him along the way, Tom managed to finish his Leaving Certificate at The Scots College, Sydney, and to graduate with a Diploma of Agriculture from Wagga Agricultural College.

Having an education was important to Tom. In fact, he sat his final agriculture exam in the afternoon, following a seizure earlier that day.

After college Tom worked at Brewon Station, where his epilepsy remained under control. He had lots of seizures at Brewon, some while horse riding. On one occasion Tom fell from his saddle head first into a water trough. Tom loved his time in the outback, but he moved back to Newcastle to chase better career prospects. He tried various jobs, but found it hard to maintain regular employment due to the unpredictable nature of his disease. Dad resigned on his first day as a door-to-door light salesman, after he had a seizure on a customer’s doorstep.

Eventually, Tom regulated his epilepsy and his job opportunities improved as a result. At twenty-seven he got a lucky break and he became an assistant land valuer with the NSW Valuer General’s Department. He worked for over thirty-five years with the VG’s, steadily progressing up the Public Service ladder. By the time he retired, he was in charge of the South Western Region of NSW; a geographical area more than twice the size of Belgium.

Tom was thankful for the opportunity the Department gave him to have a rewarding career and lifestyle, so he dedicated himself wholeheartedly to public service. He always lived in fear that the Department would find out about his epilepsy one day, but they never did.

Tom was happily married to Heather since 1963. Before dad proposed to mum he told her about his epilepsy and she accepted Tom for the man he was. They had three children – Tim, Robert and Leah. They also had three grandchildren: Ebony-Rose, Jack and Guy Rudder.

Dad was not a morning person and followed a ritual that kept him relatively seizure-free for all my lifetime (I was born in 1964), except for one occasion when we lived in Goulburn, NSW.

With encouragement from a local doctor dad got himself off nearly all his epilepsy medications. These two and a half years were a “Renaissance period” for dad, “the fuzzy cloud” lifted and his full intellect was unleashed at work and socially and his coordination improved much to my dismay because he started thrashing me at squash!

Then one day he was plunged back into “the Dark Ages!” He was in charge of the local amateur athletics carnival and he had too much on his plate. He didn’t sleep well the night before, skipped breakfast and hadn’t gone to the toilet and then rushed to the track. Tom had a seizure in the middle of the ground, in front of everyone, including my sister who was twelve at the time. Mum was in the canteen and heard that a man had gone down, straight away she knew it was dad and she dropped a peanut butter jar, saying, “Oh no don’t tell me it’s happened!” I was at home studying for the HSC, which I was about to start sitting for the next day. Mum said, “It’s happened!” She didn’t have to say any more, I knew what she meant and I drove out immediately to the ground to pick her up.

Dad had been taken away in an ambulance and went into Intensive Care. (He never went back to the ground or the painters!) He’d um and ah, and when people had to go and Tom had to go back on to heavy epilepsy medications for the rest of his life – no use crying over spilt milk!

It was a relief for us that dad did not have another fit again. We were both disappointed, but we had to keep going. I had another two weeks of exams to go and Tom had to go back on to heavy epilepsy medications for the rest of his life – no use crying over spilt milk!

I decided to illustrate and publish My Shadow in the hope that it would help and inspire other children of parents who have epilepsy, just like it helped me all those years ago!
AUSTRALIAN EPILEPSY RESEARCH REGISTER

WHAT IS THE REGISTER?
The Australian Epilepsy Research Register is a database of people who have epilepsy and who have given us permission to communicate with them for the purpose of social research.

WHO CAN JOIN?
Any person over the age of 18 with epilepsy or seizure disorder, or their carer.

WHY SHOULD I JOIN?
- You will help us to target the right services for people living with epilepsy.
- You will contribute to a study conducted over an extended period of time of the impact of living with epilepsy that will help shape future public policy.
- You will receive regular updates on research findings.

HOW DO I JOIN?
- Please contact:
  Australian Epilepsy Research Register, 818 Burke Road, Camberwell Victoria 3124
  Phone +61 (0)3 9805 9111 Fax +61 (0)3 9882 7159 Helpline 1300 852 853
  E-mail research@epilepsy.asn.au Web www.epilepsyaustralia.net

The Longitudinal Study Report on Wave 2

Australia’s first longitudinal study of epilepsy looking at needs, perceptions and experiences of people living with epilepsy is underway. This project has been made possible through the innovative direction undertaken by the Epilepsy Foundation of Victoria in 2006 in establishing a psychosocial research program aimed at providing an evidence base to argue for improved policies and services at the government and community levels. The latest report on Wave 2 Out of the Shadows: needs, perceptions and experiences of people living with epilepsy in Australia was released in April and is available at http://www.epilepsyaustralia.net/Current_Issues/Research/The_Longitudinal_Study.aspx.

This report has produced some interesting data. The Wave 2 survey of 2010 had 343 from 621 research register participants (response rate 55%):
- Wave 2 results demonstrate lower education levels amongst older people and higher school retention amongst the younger; however lower than average employment and possibly underemployment across all ages.
- Education has not led to employment amongst these respondents with only 16% of the total number having full-time jobs even though the majority of them were of working age.
- Income is also generally very low with 49% living below the current Henderson poverty line. Some people reported not having the money for shopping, for local travel and sometimes for their medicines.
- Wave 2 also explored seizure activity and levels of seizure control. This group has less seizure control than reported in the literature with only 33% reporting no seizures over twelve months. There are no data to analyse severity of seizures, however. Injuries and hospitalisations are high amongst this group. This is an important finding which deserves further exploration in the next Wave.
- The analysis found that even those with good seizure control had been hospitalised for some injuries due to seizures.
- People with epilepsy reported experiencing varying levels of stigmatising behaviour. While many felt they had been fairly treated and had not suffered any discrimination the numbers who reported unfair treatment were still high at 45%. Some of this was in the workplace while broader community attitudes are still a problem.
- A substantial proportion (32%) of people with epilepsy reported that they had experienced a lack of understanding from Government bodies that they had turned to for assistance including employment and financial advice.
- Driving remains a highly desirable and necessary component in the quality of a person’s life; being a driver or being driven by someone else remains the preferred mode of transport, although people in metropolitan areas also used public transport.
- The future of the Australian Epilepsy Research Register (AERR): More recruitment from states other than Victoria is required in order to make this a more representative sample of people living with epilepsy in the community. This is proceeding via members of Epilepsy Australia and Epilepsy Action but the AERR requires more entry points for recruitment.

Sleeping on the job – not at The Epilepsy Centre, SA & NT!

The Epilepsy Centre SA & NT, with a grant from the Department for Manufacturing, Innovation, Trade, Resources and Energy, has partnered with the Flinders University of South Australia and Roche Foam to test the effectiveness of a prototype anti-suffocation epilepsy pillow designed by The Epilepsy Centre in conjunction with Roach Foam to reduce the risk of suffocation during/after an epileptic seizure.

Initial phase of the research was to set up the experiments at the Repatriation General Hospital Sleep Lab. The prototype pillows will undergo rigorous testing over the next few months to determine their effectiveness in reducing the risk of suffocation during or after experiencing a seizure. If testing proves positive, production of the new pillow will go ahead early next year.
What is a National Disability Insurance Scheme (NDIS)?

An NDIS will be aimed at those who need the most in need, providing long term, high-quality support for around 450,000 people who have a permanent disability that significantly affects their communication, mobility, self-care or self-management. It will focus on intensive early intervention, particularly for people where there is good evidence that it will substantially improve functioning or delay or lessen a decline in functioning. It will also include a comprehensive information and referral service, to help people with a disability who need access to mainstream, disability and community supports.

An NDIS will give all Australians the peace of mind to know that if they have or acquire a disability that leaves them needing daily assistance with everyday life, or if they care for someone who has a disability, that they will be supported.

An NDIS requires fundamental change to how disability care and support is delivered in Australia. It is a task that will require a new focus on supporting people with a disability to live in their community, make the most of their potential, and provide the Government vital information on how best to progress the national roll-out. An NDIS will look beyond immediate need, and will focus on what’s required across a person’s lifetime. At its core will be:

- A lifetime approach – funding is long-term and sustainable. People with disability and their carers will have peace of mind that the individualised care and support they receive will change as their needs change.
- Choice and control – people choose how they get support and have control over when, where and how they receive it. For some, there may be the potential to manage their own funding.
- Social and economic participation – people with disability will be supported to live a meaningful life in their community to their full potential.
- Focus on early intervention – the system will have enough resources and will be smart enough to invest in remedial, preventative early intervention instead of just providing support when a family is in crisis.

The work done at these launch locations will give the Government vital information on how best to progress the national roll-out. An NDIS will look beyond immediate need, and will focus on what’s required across a person’s lifetime. At its core will be:

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Want to wear the most famous jacket of all?

The gold jacket made famous by Collingwood cheer squad identity Jeff ‘Joffa’ Corfe has been worn at weddings, draped over coffins and now is being mass produced. All, of course, for a good cause … epilepsy.

The Magpies are producing replica gold jackets and part of the proceeds will go to the Epilepsy Foundation. Hume regional worker, Lyn Bailey, has been given the first jacket and says it’s “very special”.

“\n\nTo learn more about the National Disability Insurance Scheme go to www.ndis.gov.au.
\n\ncura1
Seizure Alert System
\nThe cura1 Seizure Alert System provides peace of mind for carers and people living with epilepsy by detecting the shaking and jerking movements associated with tonic-clonic seizures, as well as detecting sounds of possible distress.

The system integrates multiple monitoring functions into a single compact device that sends a signal to a third party alarm or an (optional) wireless remote alarm system.

For more information contact 1300 122 273 or visit www.cura1.com
\n\nEpDetect Free Mobile Phone App
\nEpDetect is an accelerometer based mobile phone application that uses advanced signal processing to detect epileptic seizures. It runs on most mobile phones that support SMS messaging, movement detection and GPS position location.

EpDetect monitors the wearer’s movements, distinguishing between normal movement and movement associated with a tonic–clonic seizure. If a seizure is detected, EpDetect will contact and alert your carer with your status and GPS position.

www.epdetect.com
\n\nface2face
A familiar name at the Epilepsy Foundation of Victoria, Client Services Manager and Counselor Lisa Rath talks about the past 23 years working for the Foundation and the experience she now brings to this diverse role. Here, Lisa shares with us her enthusiasm for her work that hasn’t waned over time.

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began work for the Epilepsy Foundation of Victoria in Bendigo just over 23 years ago when I was the successful candidate for a 15 hour a week position based at the community health centre in Eaglehawk.

I still remember my first week in the job. I started the day after the Labour Day public holiday and spent the remaining four days of the working week in Melbourne at our headquarters in Kintore Street, Camberwell. I knew no one with epilepsy and was attracted to the position because I had two young primary school aged children and my role as their mother at this stage of my life was paramount. I had trained as a nurse, graduating in the late ’70’s and can remember nursing one patient who had a padded spoon in a tray on their bedside table!

In the early days travel was restricted to a 50km radius around Bendigo and anything further required special negotiation. Gradually the margin expanded to encompass the Loddon Mallee region and then the two days doubled to four when our Hume regional worker, Lyn Bailey, resigned. The Foundation asked me to assume responsibility for that region, which I happily accepted because by then my children were much older.

We conducted a part-time Shepparton office, also located in a community health centre for a couple of years, but eventually closed the office and scheduled regular trips to Shepparton and beyond as required. The regional work has always been stimulating because of the diversity of tasks such as participation in epilepsy clinics, education and training, and home visits. As a regional worker, especially in the early days, you needed to be capable of delivering a range of services.

I have been employed in a full time capacity for a number of years now – possibly ten, but I’m not sure. For the past five to six years I have been based in Melbourne at our headquarters in Camberwell, but have retained regional responsibility for the Loddon Mallee & Hume regions. These days I do much less training and am more focussed on providing direct support services to individuals and families.

I am rostered each week to do two days of intake, which involves phone calls and self-referral, and to face support. Intake is a vital part of our service and we are frequently assisting people at very vulnerable stages of their life.

On a personal note, I have two adult children – a 30 year old son who lives in Bendigo and a 32 year old daughter who is currently living in Bristol in the UK. My husband, Geoff, and I love good food, wine, live music and travel. We also love our AFL footy and go to a game most weekends. I used to be a recreational cross country runner but gave that away a few years ago due to knee problems. Swapping runners for cycling gear, I’ve been riding my bike to work regularly for at least the past two years and I’m fitter now than I have been for many years. The 24km return trip is very therapeutic, especially after a busy day on intake.

I never get out of bed in the morning and dread coming to work.

I am also thoroughly enjoying the opportunity to become involved in project work within our agency. I’ve recently worked closely with our IT guru, Jon Hindmarsh, to develop a Client Information system we call Client Manager. This system allows us to capture information about all elements of our client service – who contacts us, why they contact us, what help are they requesting, and what service have we provided. We envisage this new system will allow us to better target high quality services to the areas of greatest need.

This job has given me an opportunity to grow and develop in so many ways and I am as enthusiastic today as I remember being when I first started. It is difficult to find the right language to describe how intensely rewarding the position is – draining at times, but always rewarding.

I constantly meet wonderful people who are often dealing with extremely difficult circumstances and I consider it a privilege to have the opportunity to make some positive difference in the lives of individuals and families living with epilepsy.
Shatter Epilepsy Stigma