

ENCEPH UK

Understanding and Improving the
Outcome of Encephalitis

ENCEPH-UK

Hello and welcome to the summer 2014 edition of the ENCEPH UK newsletter.

In this issue we have included a couple of stories of people who have experienced encephalitis. Many more people with similar stories have been seen as part of ENCEPH UK and through this study we aim to help doctors recognise and better manage encephalitis to improve the outcomes for patients in the future.

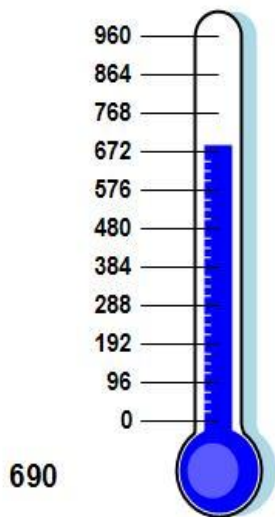
However the study wouldn't be possible without people's participation like yourself, even if you turned out to not have encephalitis in the end, your contribution to research is still greatly appreciated.

We hope you find them interesting and you can find more stories, help and support at the Encephalitis Society website:

www.encephalitis.info



Thermometer Chart



Check out our recruitment thermometer!

We have now recruited 690 adults and children with suspected encephalitis throughout the UK!

Save the Date!

South East 'Drop In' Session
Saturday 9th August

The Encephalitis Society
Support, Awareness & Research for inflammation of the Brain

A chance to meet your regional representative from the Encephalitis Society and discuss your experiences, and any related local or community issues. Please go to www.encephalitis.info/news/news-and-events/ for more info



Andrew's Story



Andrew was a perfectly normal little boy until just before his eighth birthday when his younger sister was involved in a car accident. She fractured her right arm and leg and dislocated her neck. She was in hospital for a total of ten weeks and I had to spend a great deal of time with her. Six weeks after his sister's accident Andrew became ill with a tummy bug. He appeared to recover but began to sleep a great deal.

He slept almost continually for two days, then had a seizure and was admitted into the same hospital as his sister – into the next bed. His seizures continued despite increasing doses of anti-epileptic medication. A brain scan was arranged, then an EEG test and the diagnosis of Encephalitis was made.

Christmas came and went with the whole family, including my eldest daughter, resident at the hospital. We couldn't have wished for better care and attention. Eventually, on New Year's Eve, we were all discharged. Initially, Andrew seemed to make a rapid return to normality. But it soon became apparent that he had significant communication problems. When talking to him we had to use simple language and speak clearly. He also had a word finding problem. When he returned to his primary school his teacher found that he was repeating instructions three times and still Andrew did not understand what he had to do. An Educational Psychologist was called in and found that although Andrew performed well on non verbal tasks, he scored nil on all the verbal tests. His epilepsy was also causing problems. Fortunately there was a Special Needs school very close that had a Speech and Language therapist on its staff so Andrew was transferred there.

Over the next 2 years despite Speech and Language therapy Andrew's communication problems increased. His word finding problem resulted in some interesting solutions. He lost the word for Cinema but replaced it with "Big Look" and popcorn was "Big Look Eat". A wheelchair was "Sit Walk". His ability to understand what he heard (auditory comprehension) also became worse. His seizures continued but his behaviour became very difficult. An assessment at the Neuro-rehabilitation unit in London diagnosed "perseveration" as underlying his behaviour – he became fixed on ideas / activities and could not be distracted. The Speech and Language therapist at the Neuro-rehabilitation unit also told us that his communication problems were so severe that conventional Speech and Language therapy had nothing to offer him.

The school was struggling to accommodate his problems and at home we had been without any respite for 2 years. As he became older and more difficult the fewer people outside his Mum and Dad could cope with his behaviour and with his seizures. He would climb everywhere. It was impossible to explain danger to him, not only because of his limited communication but also because he only saw things in the here and now. So if he was on a wall he could not accept that he may fall – "Look – I not falling". One day I took Andrew to a local Respite centre in the hope we could get a break. He was out of their so called "secure garden" within 10 mins by traversing a wall with an 8ft drop. We didn't go back. His perseveration also meant that you could not use the word "NO" because if his mind was fixed on certain track, "no" put a stop that he couldn't go around. The solution we found was to use "yes, but" and provide a way round. So "Can we go swimming today?" "Yes, we can go swimming but not today" and mark on the calendar when we could go. That, however, totally committed us to going swimming on that day.

By the time Andrew was 11 we were exhausted and his relationship with his sisters was deteriorating. So, we made the very difficult decision to send him to a residential school. The school we chose was a Camphill school in Scotland which provided the perfect environment for him – or any child with a brain injury. The values and objectives of Camphill schools are based on the educational, philosophical and social principles of Anthroposophy, pioneered by Rudolf Steiner. The school is a village community with children living in households with houseparents/teacher/ therapists and their own families. In the quiet structured setting he thrived. In a Camphill school the curriculum revolves around one subject at a time – the main lesson. An example would be Astronomy, so for a few weeks all the lessons would be based on Astronomy – whether that was reading, art, maths, drama, music – so the pupils become totally immersed in the subject. And most importantly for children with a brain injury, it provides more than one route to learn the subject. Another aspect of the Camphill education system is a strong focus on crafts which played to Andrew's strengths.

As a result of his poor verbal skills Andrew learns by watching and he picked up practical skills very quickly. The “perseveration” aspect of his behaviour became a strength in developing these skills and he is now, for instance, an expert weaver. Where does the time go, Andrew is now 28 and living in an adult Camphill Community in Scotland. He has lost all language but is constantly smiling. He still has epilepsy but his behaviour is much more manageable, we put this down to his being in a structured environment in which he is happy and fulfilled.



Huw and Sally's Story

Life after Encephalitis

In February 2000 Huw came home from work complaining of back and leg pains, not surprising as his job was a hairdresser involving him being on his feet all day. A few days passed with no sign of improvement so we consulted the GP who said he felt it was a virus and that Huw should go to bed, rest and take regular pain relief. Huw had never really been so ill that he would take to his bed so I knew that he must be feeling really bad. The symptoms increased and he started suffering from violent headaches and nausea and if he tried to get out of bed he ‘went blind’ and almost felt paralysed. Another GP stated that it was because he was spending too much time in bed! Then one day he announced that he had not passed urine for about five days. Another GP visited and had him admitted to hospital where he was catheterised to empty his bladder and sent home. His temperature peaked at 106F and he became delusional.

After two terrible weeks at home Huw was finally admitted to hospital. Test followed test, followed test. I visited every day, spending hours at his side not knowing what was wrong. Our children who were aged between 4 and 13 had not yet seen him but I decided perhaps it would be better if they could. On arrival at the hospital I was informed that Huw had collapsed in the bathroom and was now settled back in bed but we were not to stay above a few minutes. I took each of the children to see him in turn. There were tears and some were shell-shocked to see their Dad so helpless. The children coped in different ways. The eldest daughter arranged a very hectic social life which at the time I thought extremely selfish but she has since informed me that if she could keep busy it helped to distract her.

The eldest son became resentful that I was spending so much time away from home but I tried to explain that they all had grandparents to be with them and that at this time I felt Daddy's need was greater. It still made me feel like I was being torn in two. The youngest children were only 4 and 7 and I don't think they could really understand the implications of what was going on. I tried to remain brave for the sake of the children but one evening one of the children just said that they missed their Dad and with that I broke down in tears and said "Don't you think I miss him too?" The youngest daughter asked if Daddy was going to die and I had to say I really didn't know but that he was in the best place and that if anybody could make him better they could. We all sat on the sofa and had a 'group hug', not a cure but a comfort.

Finally Huw was diagnosed with Encephalitis. It was something that most of the family had never heard of let alone had experience of but at that time it was almost a relief just to have a diagnosis. I don't think any of us knew the real impact his illness was going to have on all of us. The business had to be closed and all of our lives changed forever. The husband/daddy/son that we had once known was not quite as he used to be. I think I once described it to the doctor as being married to Huw for 20% of the time but a complete stranger for 80% of the time. In the early days Huw didn't let me out of his sight. I would visit the bathroom and I would hear a voice shouting "Sally, where are you?" Sometimes it was like having another child. Huw's tolerance levels were lower and it could be like walking on eggshells a lot of the time.

Over the following years he attended various clinic appointments including some at ICANHO which is a local brain injury clinic. Prior to his illness he had been a mild dyslexic who relied on a very good memory to see him through but following the illness his short-term memory was practically non-existent and so he was recommended to take some English classes. ICANHO had recommended short periods of mental activity followed by long periods of rest and the same applied to physical activity. With this in mind he started writing short poems, some of which I have to say were rather dark. He progressed to short stories and the assistants at his English classes seemed to think he had a natural talent for writing and suggested he write a novel. At the time it seemed a very unrealistic suggestion but little by little the novel grew and although it has been some time in the making he has now achieved what at one time would have seemed quite impossible. The novel has been completed and is now on sale as a Kindle e-book through Amazon. It is a fantasy/science-fiction/horror novel entitled 'THE MARK OF THE GATE'.

Huw still suffers from debilitating headaches, extremely poor short-term memory, nerve damage and fatigue, to mention but a few of the life-changing conditions he has been left with as a result of his illness. Through all of this he never gave up on writing that novel and I am not alone when I say how incredibly proud of him I am. I now have a bigger percentage of my husband back but I am also married to an author; now that is something I couldn't have said prior to his illness.

Stories courtesy of The Encephalitis Society.

The Encephalitis Society provides information and support for those affected by Encephalitis as well as funding ground breaking research and raising awareness of the condition on a global scale. To find out more, become a Member or access The Encephalitis Society's support services, please visit www.encephalitis.info



More about the Encephalitis Society...

The Encephalitis Society's aim is to improve the quality of life of all people affected directly and indirectly by Encephalitis. Their objectives are:

- To support adults and children affected by Encephalitis, their families and carers by providing advice and information and working at a national and international level to improve services
- To produce evidence-based, quality information on all aspects of the condition in printed, electronic, video and audio formats
- To raise awareness about the condition and its subsequent problems among relevant professional's, statutory agencies and the general public
- To conduct research and work in partnership with other researchers and their establishments

The Encephalitis Society 
Support, Awareness & Research for Inflammation of the Brain

Encephalitis

Support and information for patients, families & professionals



www.encephalitis.info

Support for Patients & Families

- Talk to someone about the condition
- Ask about recovery and rehabilitation
- Discuss getting back to work
- Discuss your child returning to school
- Access local support services
- Request an information pack
- Become a Member
- Make contact with others
- Find meetings and events
- Read other people's stories
- Buy books and merchandise

Resources for Professionals

- Access our Diagnosis Algorithms
- Find research studies
- Arrange professional training
- Book onto our Professional Seminar
- Become a Professional Member

Contact Us

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Registered Charity Number: 1057843
Charitable Company Number: 4199027

The Encephalitis offers free membership to all people affected and their families. Get Involved and find out more <http://www.encephalitis.info/get-involved/membership-online/uk-membership/>

Useful Contacts

The Official ENCEPH UK Website: www.encephuk.org

The Brain Infections UK Website: www.braininfectionsuk.org

The Encephalitis Society Website: www.encephalitis.info

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ENCEPH-UK cohort studies

